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A Framework for Legal Enforceability of Living Wills in South Africa

by

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Declaration of originality

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SUMMARY

This thesis investigates the legal validity of living wills (advance directives) in South Africa. The study explores the current status of living wills in South Africa and contains recommendations on how legal enforceability of living wills can be improved in the South African context. The Constitution of the Republic of South Africa, 1996, the common law and the National Health Act, 61 of 2003, serve as basic points of departure for this investigation. Shortcomings in the current South African legislation and proposed draft legislation including the Law Commission's Draft Bill on End of Life Decisions, 1998, and The National Health Amendment Bill, 2019, as well as shortcomings in the common law, the field of medical ethics and medical practice are indicated and recommendations for an improved framework are made. For purposes of a legal comparative methodology, the legal frameworks of living wills in the Netherlands, England and Canada are investigated. Specific circumstances which could potentially hamper the legal enforcement of living wills are discussed, including: emergency situations, do-not-resuscitate orders, permanent vegetative states, dementia, cessation of artificial hydration and feeding, pregnancy, euthanasia, assisted suicide, palliative care, pain relief and organ donation. It is argued that a living will could be an important tool in enhancing the doctor-patient relationship, not only to the benefit of the autonomous patient whose dignity and other fundamental human rights should be protected, but also to the benefit of the doctor as the medical care provider.

KEY TERMS

Living Wills

Advance Directives

Medical Decision Making

Medical Directives

Advance Refusals of Medical Treatment

Health Care Proxies

Informed Consent

Incompetent Patients

Mental Incompetence

Doctor-Patient Relationship

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ABBREVIATIONS AND ACRONYMS

BW	Burgerlijk Wetboek (Netherlands)
CPR	Cardiopulmonary resuscitation
HPCSA	Health Professionals Council of South Africa
MAID Act	Medical Assistance in Dying Act (Canada)
PVS	Persistent vegetative state
SAMA	South African Medical Association
SCA	Supreme Court of Appeal
WHO	World Health Organization

“I will respect the autonomy and dignity of my patient.”[1]

[1] Part of the modern day Hippocratic Oath, known as the *World Medical Association* “Declaration of Geneva” “The Physician’s Pledge” (*as amended by the 68th WMA General Assembly, Chicago, United States, October 2017*) <https://www.wma.net/policies-post/wma-declaration-of-geneva/> (accessed 19-07-2019).

CHAPTER 1
INTRODUCTION

Outline

1.1 Introductory Remarks

Modern science and medical technology have made it possible to relieve pain and suffering, as well as to prolong life as never before in history. However, this has brought about a scientific, ethical and legal dilemma as for some patients it could result in the prolongation of a meaningful quality of life, but for others it could merely result in a drawn-out meaningless existence in for example a vegetative state. Others may again be helped by medical science to die a dignified and peaceful death. Death should be seen as part of life, it can be regarded as the completion of life. Living wills provide a means whereby people are given freedom of choice and control over important end-of-life decisions. Living wills can provide legal mechanisms for mentally competent individuals to exercise freedom of choice and control over such end-of-life decisions, as they provide mentally competent people with the means to state their health care wishes and instructions, to be effected in the future, when the makers are no longer mentally competent to express those health care wishes and instructions. Living wills thereby promote patient autonomy and have altered the traditional doctor-patient

relationship from medical paternalism and *beneficence* to a patient-centred approach where the patient exercises an informed choice. However, since living wills are not legally recognised in terms of the South African law, the maker's essential human rights including the right to life, right to dignity, right to privacy, right to equality, right to security of the person which includes the right to bodily and psychological integrity, freedom of religion, belief and opinion and right to access to health care, may be disregarded. In this study the legal position regarding living wills in South Africa is scrutinised by means of a legal-comparative methodology. The objective of the study is to advise on how the legal enforceability of living wills in South Africa could be improved. Ultimately, if living wills are granted the necessary legal recognition and the necessary legal framework and implementation strategies are in place, living wills should serve to advance patient autonomy and enhance the doctor-patient relationship.

1.1.1 Chapter Description

The first chapter commences by providing a brief background to this study. Thereafter the motivation for the study and the problem areas will be discussed. The primary research question, research aims, as well as parameters of the investigation will be stated. This chapter contains a description of the methodology that will be employed in the thesis and the choice of relevant legal systems will be discussed. This chapter concludes with a broad overview of the programme of study and chapter descriptions.

1.1.2. Definitions: Advance Directive, Power of Attorney for Health Care and Living Will

The concepts of "advance directives for health care" are described in different terms in different jurisdictions. Advance directives for health care are for instance sometimes also known as "advance statements", "advance directives", "living wills", "personal directives", "personal requests", "advance decisions" or "advance requests".[1] All these

[1] See Chapter 4 para 4.3 for a discussion on advance directives and living wills in the Netherlands. See Chapter 4 para 4.4 regarding advance decisions and living wills in England. See para 4.5 regarding advance directives and advance requests for medical assistance in dying in Canada.

documents have different meanings and applicability criteria in different international jurisdictions. However, all these documents have in common that that they allow a maker to make his or her future wishes known, or that they provide instructions in case of future mental incompetence or incapacity of the maker.

In order to proceed with a discussion on advance directives, working definitions of the concepts of "advance directives", "enduring powers of attorney for health care" and "living wills", must first be established. As stated above, in different jurisdictions the concepts of advance directives for health care, living wills and powers of attorney for health care differ in meaning and applicability which can result in confusing and therefore inconsistent use of terminology. This may not only be confusing to patients, their loved ones and health care workers, who will be confronted by these documents, but at large the medical fraternity, legal scholars and legal practitioners may also grapple with these concepts which have varying meanings and legal implications. The confusion surrounding the use of different terminology, varying meanings and varying legal implications may ultimately lead to legal enforcement problems.

In general an "advance directive" in the context of health care can be defined as:

> "an instrument by which a competent individual can continue to exercise autonomous control over healthcare decisions in the event of future incompetence".[2]

Many authors aver that an advance directive has two legs, namely firstly, the living will and secondly an enduring power of attorney for health care.[3] These living wills and enduring powers of attorney documents can also be written in one single document sometimes headed "living will" or "advance directive" or given another name such as

[2] Tonelli MR "Pulling the plug on Living Wills – A Critical Analysis of Advance Directives" (Sept 1996) *CHEST* 110 (3) 821. Note on language and terminology: All quotes referred to in this thesis are quoted as they were published. Therefore, some stylistic and spelling inconsistencies may occur.

[3] Jordaan L "The legal validity of an advance refusal of medical treatment in South African law (part 1)" (2011) *De Jure* 34; Landman WA "End-of-life decisions, ethics and the law: A case for statutory legal clarity and reform in South Africa: A Position Paper" 18 May 2012 (Ethics Institute of South Africa) 41; Beauchamp TL & Childress JF *Principles of Biomedical Ethics* (2009) 186.

"advance wishes", "advance requests", "personal requests" or a similar term. The terminology anomaly that exists in the South African medical and legal fraternity, is a direct result of the fact that there is currently no explicit legislation or other law on advance directives and living wills in South Africa.[4]

A "living will" is the most common form of an advance directive which enables mentally competent persons to retain control over their medical treatment in the event of a future state of incompetence.[5] According to Strauss a living will is:

> "Legally [...] a declaration in which a person *in anticipando* by way of an advance directive refuses medical attention in the form of being kept alive by artificial means." [6]

According to McQuoid-Mason and Dada "living wills" are defined as "advance directives given by patients regarding their future treatment should they become incompetent to consent to, or refuse, such treatment."[7]

According to the South African Medical Association (hereafter "SAMA") a living will is described as:

> "a declaration or an advance directive which will represent a patient's wish to refuse any medical treatment and attention in the form of being kept alive by artificial means when the patient may no longer be able to competently express a view".[8]

A "living will" is thus not a will in the technical testamentary sense of the word, but a document in which the drafter endeavours to make certain requests or issue directives to the people who would be responsible for his or her medical treatment.[9]

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[4] See discussion in Chapter 3 para 3.2.
[5] Dada MA & McQuoid-Mason DJ *Introduction to medico-legal practice* (2001) 27; Sneiderman B & McQuoid-Mason D "Decision-making at the end of life: the termination of life-prolonging treatment, euthanasia (mercy-killing), and assisted suicide in Canada and South Africa" (2000) *CILSA* XXXIII 195.
[6] Strauss SA *Doctor, patient and the law* (1991) 344.
[7] McQuoid-Mason DJ & Dada MA *A-Z of Nursing Law* (2011) 171.
[8] South African Medical Association "Living Wills and Advance Directive" (2012) <https://www.samedical.org/images/attachments/guidelines-with-regard-to-living-wills-2012.pdf> (accessed 29-04-2016).

In a broader sense living wills are applicable to any health care situation where patients anticipate that they may lack capacity to make decisions for themselves in future. In terms of this broader definition living wills are thus not limited to decisions to cease life-sustaining treatment.[10] They represent standing requests for medical staff to act in a specific manner in specific circumstances. The researcher employs the broader definition of living wills in this study.

The advance directive document is as such a document that contains general health care instructions which can furthermore contain an enduring power of attorney for health care and/or a living will, or the advance directive may be for a specific situation for example organ donation and not contain an enduring power of attorney and/or living will. The living will and/or enduring power of attorney documents can be drafted as two separate documents or they can be integrated into one document either named a living will or an advance directive.

In terms of common law a power of attorney, based on the legal principles of agency, remains valid where a principal retains contractual capacity and remains mentally competent to make his or her own decisions. However, as soon as the principal becomes mentally incompetent or incapacitated and thus unable to manage his or her own affairs, the power of attorney lapses.[11] The South African Law Commission has investigated this problematic aspect regarding the lapsing of power of attorneys upon mental incompetence, but to date no legislation has been enacted to give effect to this

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[9] Strauss SA *Doctor, patient and the law* (1991) 344.
[10] President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research "Deciding to Forego Life-Sustaining Treatment: A report on the ethical problems in medicine and biomedical and behavioural research" (2006) 137.
[11] *Pheasant v Warne* 1922 AD 481; *Tucker's Fresh Meat Supply (Pty) Ltd v Echakowitz* 1958 (1) SA 505 (AD); South African Law Commission ("SALC") Issue Paper 18 (Project 122) *Incapable Adults* (2001); SALC Discussion Paper 105 (Project 122) As*sisted Decision-Making: Adults with Impaired Decision-Making Capacity* (2004); SALC *Assisted Decision-Making Report* (December 2015).

legal lacuna.[12] At present the available common legal remedy in the instance where a person lacks decisional capacity, is an application to the High Court to have a curator appointed to act on that person's behalf. It is furthermore a possibility to have an administrator appointed in terms of the Mental Health Care Act.[13] It is thus proposed that the enduring power of attorney must be developed in the South African law as an alternative to curatorship and administrator applications.

As there is currently no legislation on the drafting of living wills and advance directives in South Africa, there are no legal prescriptive guidelines and rules to follow. It is therefore up to the individual to draft his or her own document as he or she sees fit which is problematic in terms of applicability and enforceability standards.

Dada and McQuoid-Mason and state that:

> "Although living wills have not been recognised by statute, they should be recognised at common law – provided they reflect the current wishes of patients. Such wishes may be indicated if such patients are carrying a copy of the living will or such a will has been lodged with their doctor or other health-care provider. The National Health Act, 2003 (Act 61 of 2003) now allows patients to appoint proxies to make health-care decisions on their behalf when they become incompetent – provided such proxies are appointed in writing."[14]

The researcher supports the position that a patient should streamline all his or her advance directive health care documents into one all-encompassing living will document which must be written in plain language and made readily available.[15] In emergency situations when these advance directive documents become relevant, the medical

[12] SALC Discussion Paper 105 (Project 122) 2004 which included the Adults with Impaired Decision-making Capacity Bill, 2004; SALC Assisted Decision-Making Report (2015) which included the Supported Decision-making Draft Bill, 2015.
[13] Mental Health Care Act, 17 of 2002 came into effect on 15 December 2004.
[14] Dada MA & McQuoid-Mason DJ *A-Z of Nursing Law* (2011) 171 & 172.
[15] See Chapter 5 para 5.3.6 on the drafting and para 5.3.4 safekeeping of living wills.

decision makers and role players do not have time to search through different documents and complex clauses to find relevant instructions.[16]

This thesis promotes the position that medical practitioners should honour living wills and advance directives if the documents adhere to the legal validity requirements, and if the proper safeguards proposed in this thesis have been met.[17]

1.1.3 Definition: Incapacity

Since makers of living wills need to be mentally competent at the time of making the living will, it is important to determine how capacity and incapacity are defined. In South Africa every person has the right to make his or her own health care decisions provided that he or she possesses the decision-making capacity to do so and can provide the necessary informed consent (or informed refusal).

The National Health Act[18] describes the principle of informed consent as follows in Section 7:

> "7 (1) Subject to section 8, a health service may not be provided to a user without the user's informed consent unless –
>
> (a) the user is unable to give informed consent and such consent is given by a person –
>
> (i) mandated by the user in writing to grant consent on his or her behalf; or
>
> (ii) authorised to give such consent in terms of any law or court order;
>
> (b) the user is unable to give informed consent and no person is mandated or authorised to give such consent, and the consent is given by the spouse or partner of the user or, in the absence of such spouse or

[16] See Chapter 5 para 5.3.6 on the drafting and para 5.3.4 safekeeping of living wills.
[17] See Chapters 3, 5 and 6.
[18] National Health Act, 61 of 2003.

partner, a parent, grandparent, an adult child or a brother or a sister of the user, in the specific order as listed;

(c) the provision of a health service without informed consent is authorised in terms of any law or a court order;

(d) failure to treat the user, or group of people which includes the user, will result in a serious risk to public health; or

(e) any delay in the provision of the health service to the user might result in his or her death or irreversible damage to his or her health and the user has not expressly, impliedly or by conduct refused that service.

(2) A health care provider must take all reasonable steps to obtain the user's informed consent.

(3) For the purposes of this section "informed consent" means consent for the provision of a specified health service given by a person with legal capacity to do so and who has been informed as contemplated in section 6."[19]

Since living wills and advance directives only become operational once a patient is mentally incompetent or mentally incapacitated, it is thus vital to the understanding of a concept of a living will or advance directive to determine what exactly is meant by incapacity or mental incompetence. Mental incapacity and incompetence imply that a person cannot contemporaneously provide informed consent or informed refusal. At the moment when mental incompetence or incapacity sets in, the living will or advance directive becomes operational. Doukas and Reichel define incapacity as the patient's inability to understand the treatment choices presented to him or her, the inability to appreciate the implications of the available alternatives and the inability to communicate a decision about his or her health care.[20]

[19] The National Health Act, 61 of 2003 employs the term "user" when referring to a person who receives treatment in a health establishment (See s1 of the Act).

[20] Doukas DJ & Reichel W *Planning for uncertainty: A guide to Living Wills and Other Advance Directives for Health Care* (1993) 56.

Different jurisdictions have different mechanisms to determine incapacity with reference to the operation of living wills and advance directives. Depending on the specific laws of each jurisdiction, one or two treating doctors or physicians are normally required to examine the patient, and determine and/or verify that the patient lacks the capacity to make the relevant medical decisions.[21]

It is also important to note that it is possible for a patient to temporarily lose capacity and regain it again later in which event the living will or advance directive will only be applicable to the period during which the patient did not have capacity. A patient who regains capacity, after a lapse in capacity, will therefore not require the use of a living will which might have been drafted previously, to make his or her instructions known, but will rather convey his or her instructions contemporaneously. The patient's autonomy is thus respected.

1.2 Background: Underlying Hypotheses and Significance of the Study

The different aspects discussed below as part of the background to this study are dealt with in detail in relevant chapters of the thesis. Many different sources of law, draft law and medical ethics exist that pertain to the legal enforcement of living wills. Since living wills are not legally enforceable in South Africa, the sources of law, draft law, ethical guidelines, opinion pieces and media reports are all of relevance. Not all the sources that are discussed elsewhere in this thesis are mentioned in this background discussion.

1.2.1 Medical Law and Medical Ethics

Human rights law,[22] medical law and medical ethics form the foundation for the legal enforcement of living wills and advance directives in South Africa. Medical law is a

[21] In this thesis the terms "doctors" and "physicians" are used interchangeably.
[22] See discussion on human rights law in Chapter 2.

unique field of the law in which the rules of medical ethics must also be taken into consideration, when actions are judged to ascertain their lawfulness.

The question then arises what exactly the interface is between the law and medical ethical principles. Can the law and ethics overlap and/or can they work together in unison or should the law and ethics stand separately in other words are they non-dependant and non-related to one another? How does the medico-ethical framework inform the legal framework? Do legal rules follow ethical rules? Can normative ethical values contained in rules of ethics, also be legal rights? Does unethical conduct amount to illegal conduct and is ethical conduct always legal conduct? These questions are important in the context of this thesis and need careful consideration in the creation of a legal framework for the legal enforcement of living wills in South Africa.

Medical law "relates to the legal aspects of medical practice" and consists of a "body of rules of law" relating to the medical profession, the relationship between the doctor (or hospital) and the patient, the relationship between the medical profession and health care workers and the relationship between doctors and health care legislation.[23]

According to Nöthling Slabbert "…medical law … may be taken to refer to the body of rules of law relating to:

a) the medical profession;
b) the relationship between doctor and/or hospital on the one hand and patient on the other;
c) the relationship between the medical profession and other health care workers; and
d) the doctor and health care legislation."[24]

Nöthling Slabbert explains that:

[23] Moodley K *Medical ethics, law and human rights. A South African perspective* (2011) 132.
[24] Nöthling Slabbert M "South Africa" in *International Encyclopaedia of Laws* (Suppl 81 2014) 42-43.

> "The relationship between doctor/hospital and patient is essentially a private-law matter and is governed by the law of obligations: that is, to say by the law of contract and the law of delict. In the ordinary course of events, the relationship between the parties is a contractual one. Since, however, breach of a duty of care and negligence may underlie both breach of contract and a delict, the same act or omission by a doctor/hospital may result in liability for both. In the absence of a contract between the parties, the relationship between the parties is governed by the law of delict."[25]

It is necessary to determine what the term "ethics" means in the field of medical law and medical ethics. According to Britz the term "ethics" concerns "how things ought to be done for ethical reasons, regardless of legislation".[26] According to Dhai, McQuoid-Mason and Knapp van Bogaert ethics forms part of moral philosophy.[27] Moral philosophy entails "applying certain types of analysis and argument in order to develop general criteria for differentiating between right and wrong, and good and evil". The authors explain that ethics is "concerned with the moral choices people make and includes the study of right and wrong actions". Ethics can thus be viewed as the "the study of morality" which involves "careful systematic reflection on and analysis of actions and behaviour". Morality is in fact the "value dimension of human decision making".

Dhai, McQuoid-Mason and Knapp van Bogaert explain that the principles of ethics are closely related to the law, but that the law and ethics are not however identical.[28] Giesen explains that professional medical ethics does not stand separated from the law. The

[25] Nöthling Slabbert M "South Africa" in *International Encyclopaedia of Laws* (Suppl 81 2014) 59.
[26] Britz PM *Medical Record Keeping in South Africa: A Medico-Legal Perspective* (2018) MPhil University of Pretoria 7.
[27] The other forms of philosophy being the "philosophy of mind" and the "philosophy of science". Dhai A, McQuoid-Mason D & Knapp van Bogaert D "Ethical concepts, theories and principles and their application to healthcare" in Dhai A & McQuoid-Mason D *Bioethics, Human Rights and Health Law: Principles and Practice* (2011) 3.
[28] Dhai A, McQuoid-Mason D & Knapp van Bogaert D "Ethical concepts, theories and principles and their application to healthcare" in Dhai A & McQuoid-Mason D *Bioethics, Human Rights and Health Law: Principles and Practice* (2011) 3.

doctor-patient relationship is worldwide thought to be the cornerstone of medical practice. Giesen states that professional medical ethics and the law are "intrinsically interwoven" in the doctor-patient relationship, and that the law and medical ethics furthermore continually influence and evolve the doctor-patient relationship.[29] Giesen explains that:

> "[w]hat the rules of ethics demand of a physician, will at the same time and to a large extent also be the legal obligation [on the physician] that has to be fulfilled".[30]

According to Carstens:

> "[it] is in the medical professional field much more than in any other social relationship, that ethical considerations are inextricably linked with considerations of a legal nature, and this is as true today as it was in the past".[31]

In many countries the principles of ethics are incorporated into the law. In South Africa the sources of medical ethics or health care ethics are the Constitution,[32] Acts of Parliament such as the National Health Act[33] and various regulatory and policy documents such as those drafted by the Health Professions Council of South Africa and the South African Medical Association, which allow for health care practitioners to be disciplined by the professional body concerned, when the conduct of their members is found to be unethical. International law and codes on ethics also exist.[34]

Dhai *et al* explain that when a doctor for example breaches the law (medical law included) by performing unlawful actions, the doctor can be held legally liable. However when codes and rules on medical ethics are breached, for example the codes of the

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[29] Giesen D *International Medical Malpractice Law: A Comparative Law Study Of Civil Liability Arising From Medical Care* (1988) 669.
[30] My addition. Giesen D *International Medical Malpractice Law: A Comparative Law Study Of Civil Liability Arising From Medical Care* (1988) 669.
[31] Carstens P "Revisiting the infamous Pernkopf Anatomy Atlas: historical lessons for medical law and ethics" *Fundamina* (2012) 18 (2) 40.
[32] Constitution of the Republic of South Africa, 1996.
[33] National Health Act, 61 of 2003.
[34] See Chapter 4 para 4.2.

HPCSA, the professional body can take the necessary disciplinary action against the offending doctor.[35] Not all unethical conduct can therefore necessarily be regarded as unlawful or illegal, since it could amount to violating professional medical standards, and not amount to a transgression of the law.

However Dörfling correctly notes that medical law is not always up to date or on par with the ever evolving advancements and new developments in medical science and medical technology.[36] The end–of-life and advance medical decision making by way of advance directives and living wills, is one such field where the law lags behind medical developments and this is the primary reason it was selected as the research field for his study. Medical developments have progressed to such an extent in the last few decades that it has become technically possible to make life and death decisions about patients that would have not have been possible in earlier times. All these medical and technological advancements have brought about a dilemma, as it has become possible to prolong human life artificially by technical means on the one hand, and on the other hand it has become possible to bring about death in a dignified and painless way by the administration or withholding of medicine and the withholding of artificial feeding and hydration. Modern medical technology can fulfil life sustaining functions for example specialised machines can perform heart and lung functions long after a patient's brain activity has ceased to exist.[37] The question that now arises focuses on how patients can provide their instructions and wishes in advance and ensure that these instructions will be legally binding on medical and other decision makers, and be of force and effect at the applicable time when the patients are no longer competent to provide their own instructions, thus when such advance decisions will have to be relied upon.

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[35] Dhai A, McQuoid-Mason D & Knapp van Bogaert D "Ethical concepts, theories and principles and their application to healthcare" in Dhai A & McQuoid-Mason D *Bioethics, Human Rights and Health Law: Principles and Practice* (2011) 3-4.

[36] Dörfling DF "*Genadedood" in die Strafreg – 'n regsfilosofiese en regsvergelykende perspektief* (1991) LLM Verhandeling Universiteit van Johannesburg 8.

[37] Dörfling DF "*Genadedood" in die Strafreg – 'n regsfilosofiese en regsvergelykende perspektief* (1991) LLM Verhandeling 8.

Dörfling describes the rapid increase of medical technological advancements and the dilemma it creates as follows:

> "Hierdie tegnologiese ontwikkelings plaas medici en die belanghebbende derde party voor een van die grootste vraagstukke in die geskiedenis van die mediese professie, naamlik tot watter mate moet medici en die belanghebbende derde party die selfbeskikkingsreg oor die lewe van 'n sterwende verkry."[38]

Dörfling explains that as technology has advanced, the emphasis has started shifting from the patient, who lives and dies, to the person who delivers medical input such as doctors or other interested parties.[39] The patient's autonomy and doctor's paternalistic role are thus in conflict.[40]

This dilemma caused by the developments in modern science and technology has scientific, technical, moral and ethical dimensions; for some patients it could result in a prolongation of a meaningful life, but for others it could merely result in a meaningless existence in a vegetative state, whereas others may again be helped by medical science to die a dignified and peaceful death.[41] The ultimate question should be whether treatment is beneficial to the person's quality of life or whether the treatment is unnecessarily prolonging the deterioration of quality of life and/or pain and/or human suffering. The courts have been willing to delve into the world of medical ethics in reaching controversial decisions, when called upon the adjudication of the type of treatment a patient should receive such as in the famous *Bland*[42] case where the court said that:

> "This is not an area in which any difference can be allowed to exist between what is legal and what is morally right. The decision of the court should be able to

[38] Dörfling DF "*Genadedood" in die Strafreg – 'n regsfilosofiese en regsvergelykende perspektief* (1991) LLM Verhandeling 1.
[39] Dörfling DF "*Genadedood" in die Strafreg – 'n regsfilosofiese en regsvergelykende perspektief* (1991) LLM Verhandeling 8.
[40] See further discussions on the doctor-patient relationship in Chapters 3 & 5.
[41] Slabbert M & van der Westhuizen C "Death with dignity in lieu of euthanasia" (2007) 22 *SAPR/PL* 366.
[42] *Airedale NHS Trust Respondents v Bland* (1993) 1 All ER 821.

carry conviction with the ordinary person as being based not merely on legal precedent but also upon acceptable ethical values."[43]

Giesen confirms that:

"…it will often be necessary for the law and society and, thus for the courts if called upon, to take cognizance of established codes of medical ethics: *not,* as professionals would perhaps wish, as conclusive evidence as to the legal duty or legally acceptable standards, but in order to understand from what educational professional background and ethical commitment physicians normally proceed when exercising their profession *vis-a-vis* their patients".[44]

1.2.2 Historical Development of Living Wills

In order to be able to create a legal framework for living wills in the future, it will be helpful to investigate the historical development of living wills. The concept of a living will has its origin in the United States of America, where an attorney from Illinois, Luis Kutner, first proposed the concept in 1969 in response to a fear that doctors might be encouraged by rapid medical advancements and technological advancements to impose life-sustaining treatments on patients who might not desire such life-prolonging treatments.[45] The fundamental principle of a living will is that the patient has the right to refuse any specific medical treatments including life-sustaining treatments, and that medical personnel are obliged to honour the wishes of the mentally competent patient.[46] When a patient is no longer able to make decisions regarding his or her treatment and care, doctors are then dependent on prior consent, directives by an agent, instructions by family members or their own judgement, with due observance of the ethical code that

[43] See Airedale *NHS Trust Respondents v Bland* (1993) 1 All ER 821 850.
[44] Giesen D *International Medical Malpractice Law: A Comparative Law Study Of Civil Liability Arising From Medical Care* (1988) 669.
[45] Kutner L "Due Process of Euthanasia: The Living Will, A Proposal" (Summer 1969) *Indiana Law Journal* 44 4 539-554; Emanuel L "How living wills can help doctors and patients about dying" (17 June 2000) *BMJ* 320 1618.
[46] South African Law Commission Report on *Euthanasia and the Artificial preservation of life* Project 86, (November 1998) 156.

binds them. The object of the advance directive (living will) is therefore to give guidelines to medical practitioners as to their conduct in circumstances where the patient is no longer able to do so himself or herself. It is a particular object of this document to absolve medical practitioners from liability should the treatment or the withholding of such treatment hasten the death of the patient.[47] Some doctors are reluctant to recognise living wills pertaining to the fact that a patient might have changed his or her mind, such as care instructions when faced with a certain illness, from the time of drafting the will to its implementation, but if there is clear evidence that the will reflects the patient's wishes, the doctor should respect such wishes.[48] Another uncertain aspect of the implementation of living wills concerns changed circumstances of a patient, whether personal and/or medical. If a patient's personal circumstances change (for example when a patient immigrates to another jurisdiction or a change in legal status occurs for example when a patient is sequestrated, gets married or widowed) or when medical circumstances change (for example when a patient is diagnosed with a new illness or cured from an illness, or a new medical treatment becomes available), the living wills' legal framework should make it easy, practical and convenient for a patient, to alter, revoke or add additional instructions and requests contained in his or her living will which will ensure that the living will is tailored to his or her specific circumstances and enhance the applicability and enforceability thereof. The wishes and instructions of a patient who has capacity will always override what is stated in a previously drafted living will or advance directive.

The usefulness and practicality of a living will can be illustrated by the *Cruzan v Director Missouri Department of Health*[49] 1990 decision. In 1983, the then 25-year-old Nancy Cruzan was involved in a motor accident in the state of Missouri. When the paramedics arrived on the scene no vital signs were evident, but they managed to resuscitate her. After three weeks in a coma, the doctors diagnosed her as being in a persistent

[47] South African Law Commission Report on *Euthanasia and the Artificial preservation of life* Project 86, (November 1998) 156.
[48] Dada MA & McQuoid-Mason DJ *Introduction to medico-legal practice* (2001) 27.
[49] *Cruzan v Director Missouri Dept of Health* 497 US 261 (1990).

vegetative state (hereinafter “PVS”) and inserted a feeding tube to facilitate long term care. In 1988 Nancy Cruzan’s parents requested the doctor to remove her feeding tube. The hospital refused to accede to the parents’ request without the requisite court order in place, and stated that the removal of the tube would cause Cruzan’s death.[50] Cruzan’s parents subsequently applied to court and were granted an order for the feeding tube to be removed. The trial court stated that a “fundamental natural right” exists “to refuse or direct to refuse or direct the withholding or withdrawal of artificial death prolonging procedures when the person has no more cognitive brain function ... and there is no hope of further recovery”. On the facts, the court ruled that Nancy had effectively “directed” the withdrawal of life support by telling a friend earlier in the year prior to her accident that if she were ill or injured, "she would not wish to continue her life unless she could live at least halfway normally". The state of Missouri and Nancy's guardian *ad litem* both appealed this decision to the Supreme Court of Missouri. The Supreme Court of Missouri reversed the trial court's decision and ruled that no one may refuse treatment for another person, except when there is a living will or “clear and convincing, inherently reliable evidence” which was found to be absent at the time.

The Cruzans subsequently appealed the Supreme Court of Missouri’s finding and in 1989 the Supreme Court of the United States agreed to hear the case. On hearing further factual evidence of Nancy’s wishes the Supreme Court of the United States confirmed the Supreme Court of Missouri’s finding that “clear and convincing evidence” needs to be put before court, before a ruling on removal of a feeding tube can be made in the case of mentally incompetent patients. The Supreme Court said that this higher standard of evidentiary proof was necessary to protect incompetent patients as family members might not always make decisions that the incompetent person would have agreed to, such as the withdrawal of life support, which is irreversible. On the facts, clear and convincing evidence was found to be in existence and the feeding tube was

[50] See discussion on the right to life, the right to choose to live and the state’s obligation to protect a person’s right to life in Bopp J and Avila D “The due process ‘right to life’ in Cruzan impact on the ‘right to die’ law” (Fall 1991) 53(1) *University of Pittsburgh Law Review* 193-233.

ordered to be removed. This ruling was handed down seven years after the initial accident. The implications of this case are that advance directives, either written or spoken, are needed. Written directives are much easier to prove than vocal requests and provide guidance, certainty and legal protection from different kinds of value-laden health care decisions.

The result of the *Cruzan* case was that the federal government enacted the Patient Self-Determination Act.[51] The Patient Self-Determination Act requires hospitals, nursing facilities, hospices, home health care programmes, and health maintenance organisations to inform patients about their right to make future (advance) care and treatment decisions through the use of advance directives. Following the *Cruzan* case, the different states of the United States of America developed both medical proxy laws, whereby individuals could designate someone to make medical decisions for them if they become incapacitated, as well as laws on living wills to convey legally enforceable end-of-life care instructions and wishes. In the next paragraphs South African medical law and ethics as they pertain to living wills, will be introduced.

1.2.3 South African Medical Law and Medical Ethics pertaining to Living Wills

The Health Professions Council of South Africa ("HPCSA") states that the practice of health care is based on a mutual relationship of trust between patients and health care practitioners. The HPCSA further states:

> "To be a good healthcare practitioner, requires a life-long commitment to sound professional and ethical practices and an overriding dedication to the interests of one's fellow human beings and society. In essence, the practise (*sic*) of healthcare professions is a **moral enterprise**."[52]

[51] Patient Self-Determination Act, 1990.
[52] My emphasis. HPCSA "Guidelines for good practice in the healthcare professions: General ethical guidelines for the healthcare professions" Booklet 1 (September 2016) <https://www.hpcsa.co.za/Conduct/Ethics> (accessed 22-06-2019).

The word "moral" here is important. Ethics are derived from morals, and morals inform the law. Dhai *et al* explain that: "[e]thics, as a study of morality involves a careful systematic reflection on and analysis of actions and behaviour".[53] Giesen explains that:

> "it is in the sense of moral obligations as perceived by the profession, of course, that traditional medical ethics tends to be depicted in the various national and international codes of medical ethics and enforced by the respective professional bodies".[54]

According to the HPCSA the health care practitioners have to adhere to certain "core ethical values and standards" including "respect for persons". Patients should be respected as persons and their intrinsic worth, dignity, and sense of value, should be acknowledged. The "best interest or well-being of patient" should be paramount. This includes the principle of *non-maleficence* in terms of which health care practitioners "should not harm or act against the best interests of patients, even when the interests of the latter conflict with their own self-interest". The "best interest or well-being of the patient" principle also includes the principle of *beneficence*: health care practitioners should act in the "best interests of patients even when the interests of the latter conflict with their own personal self-interest". The HPCSA also states that health care practitioners should recognise the "human rights of all individuals".[55] The principle of patient "autonomy" is important in terms of which health care practitioners should honour the rights of patients to "make their own informed choices, and to live their lives by their own beliefs, values and preferences". The HPSCA further emphasises the principle of "integrity" stating that health care practitioners "should incorporate all these core ethical values and standards as the foundation for their character and practise (*sic*) as responsible healthcare professionals". Furthermore, the principle of "truthfulness" is fundamental. Truth and truthfulness should be regarded as the "basis of trust in their

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[53] Dhai A, McQuoid-Mason D & Knapp van Bogaert D "Ethical concepts, theories and principles and their application to healthcare" in Dhai A & McQuoid-Mason D *Bioethics, Human Rights and Health Law: Principles and Practice* (2011) 3.

[54] Giesen D *International Medical Malpractice Law: A Comparative Law Study Of Civil Liability Arising From Medical Care* (1988) 669.

[55] See Chapter 2 "The South African Constitutional Rights with reference to End-of-life Decisions and Living Wills".

professional relationships with patients". In terms of the principle of "confidentiality" health care practitioners are required to "treat personal or private information as confidential in professional relationships with patients - unless overriding reasons confer a moral or legal right to disclosure". In terms of end-of-life and difficult treatment decisions, the principle of "compassion" is very important. The HPCSA states that: "Healthcare practitioners should be sensitive to, and empathise with the individual and social needs of their patients and seek to create mechanisms for providing comfort and support where appropriate and possible".[56]

We live in a multi-cultural, multi-racial democratic society, therefore the ethical principle of "tolerance" is also essential. "Healthcare practitioners should respect the rights of people to have different ethical beliefs as these may arise from deeply held personal, religious or cultural convictions." The HPCSA also prescribes to the principle of "justice" stating that health care practitioners "should treat all individuals and groups in an impartial, fair and just manner". All health care practitioners are requested to have "professional competence and self-improvement" and should "continually endeavour to attain the highest level of knowledge and skills required within their area of practice". The final ethical principle to which health care professionals should adhere is the principle of "community" in terms of which health care practitioners "should strive to contribute to the betterment of society in accordance with their professional abilities and standing in the community".

The field of medical law and medical ethics is a vibrant, developing and all-encompassing field of the law. Not only does it concern medical decision making and the application of medical law, public law, the law of contract, criminal law and the law of persons, but the integration of medical law and medical ethics is of cardinal importance since medical practitioners have to adhere to both the principles of medical law and medical ethics.

[56] HPCSA "Guidelines for good practice in the healthcare professions: General ethical guidelines for the healthcare professions" Booklet 1 (September 2016) <https://www.hpcsa.co.za/Conduct/Ethics> (accessed 22-06-2019).

Beauchamp and Childress have created a valuable framework to resolve ethical problems worldwide. This framework is referred to as Beauchamp and Childress' "four principles".[57] They argue that the four principles of patient autonomy, *non-maleficence*, *beneficence* and justice can be applied to resolve ethical health care dilemmas. Beauchamp and Childress advise that these principles have to be interpreted in terms of existing social practices, the particular circumstances and specific contexts.[58] These principles are utilised as a point of departure for the ethical acceptance of a legal framework for living wills in this thesis.

The following principles of medical ethics, based on and adapted from Beauchamp and Childress, will be discussed in this thesis:

1.2.3.1 Patient Autonomy

Dworkin writes that:

> "It is generally agreed that adult citizens of normal competence have a right to autonomy, that is, a right to make important decisions defining their own lives for themselves."[59]

Strauss emphasises the importance of a person's right to autonomy in society by saying that a "…in our society, the mentally competent individual's right to control his own destiny in accordance with his own value system, his *selfbeskikkingsreg*, must be rated even higher than his health and life (unless it would clearly offend against the community interest)".[60] According to Norval and Gwyther autonomy can be described as

[57] Dhai A, McQuoid-Mason D & Knapp van Bogaert D "Ethical concepts, theories and principles and their application to healthcare" in Dhai A & McQuoid-Mason D *Bioethics, Human Rights and Health Law: Principles and Practice* (2011) 14.
[58] Beauchamp TL & Childress JF *Principles of Biomedical Ethics* (2009) 99-280.
[59] Dworkin R "Life past reason" in *Life's Dominion* (1993) 222.
[60] Strauss SA *Doctor, patient and the law* (1991) 92.

self-rule which promotes the idea that individuals are allowed to make their own decisions.[61]

Legal scholars emphasise the concept of patient autonomy in literature on advance directives and living wills.[62] Tonelli discusses the use of a living will and its relevance for patient autonomy and claims that "the recent emphasis on patient autonomy within medical ethics has had a profound influence not only on the practice of medicine, but on the concept of autonomy itself".[63] He argues that autonomy has become "so integral to medical decision making that it is advocated as a guiding principle even in individuals who are no longer autonomous". Tonelli argues that "the right of self-determination is not lost in incompetent, and therefore non-autonomous, patients" and therefore an advance directive is of force and effect.[64]

Beauchamp and Childress explain that respect for autonomy relates to individuals' autonomous choice and decision making capabilities.[65] Linguistically speaking, the word autonomy is derived from the Greek *autos* (meaning self) and *nomos* (meaning rule).[66] Dhai, McQuoid-Mason & van Bogaert explain that the principle for respect of autonomy relates to self-determination and constitutes the basis of informed consent and respect for confidentiality in the health care practice.[67]

King argues that the basis for moral and legal validity of advance directives stems from a patient's right to autonomy or self-determination.[68] She argues that a patient's right to

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[61] Norval D & Gwyther E "Ethical decisions in end-of-life care" (2003) *CME* 21 5 267.
[62] Jordaan L "The legal validity of an advance refusal of medical treatment in South African law (part 1)" (2011) *De Jure* 34-35 & 40-47.
[63] Tonelli MR "Pulling the plug on Living Wills – A Critical Analysis of Advance Directives" (Sept 1996) 110(3) *CHEST* 816.
[64] Tonelli MR "Pulling the plug on Living Wills – A Critical Analysis of Advance Directives" (Sept 1996) 110(3) *CHEST* 816.
[65] Beauchamp TL & Childress JF *Principles of Biomedical Ethics* (2009) 99-174.
[66] Beauchamp TL & Childress JF *Principles of Biomedical Ethics* (2009) 99.
[67] Dhai A, McQuoid-Mason D & Knapp van Bogaert D "Ethical concepts, theories and principles and their application to healthcare" in Dhai A & McQuoid-Mason D *Bioethics, Human Rights and Health Law: Principles and Practice* (2011) 14.
[68] King NMP *Making sense of advance directives* (1991) 3. See Chapter 2 para 2.3.6.

autonomy implies a duty on others (physicians and caregivers in particular) to not interfere with the patient's right to exercise his or her autonomy. King states that the duty of non-interference however does not help the interpretation or enforceability of the directives, nor does it help guide physicians in interpreting and implementing the directives, nor does it help patients to formulate and articulate their wishes by means of advance directives.[69]

King argues that the enforceability and interpretation of advance directives is not only based on patient autonomy but rather on the community: "the enforceability of directives depends on more than just their basis in autonomy; it also depends, in an important way, upon community".[70] The context of community is therefore vital in giving effect to advance directives. The members of the community including medical personnel, family, friends and other decision makers are the ultimate decision makers when a patient is no longer in a position to express his or her medical wishes and decisions.

The importance of community is stressed in the ethics theory of communitarianism. Communitarianism entails that the individual does not live in isolation, but is part of a community, in which human beings are in social relationships and interdependent on one another. This is emphasised in terms of the African worldview of *ubuntu*: "I am because we are; and since we are, therefore I am", wherein the interests and well-being of the community are considered the primary values.[71] An individual is thus both an autonomous and a communal being.[72]

[69] King NMP *Making sense of advance directives* (1991) 3.
[70] King NMP *Making sense of advance directives* (1991) 3.
[71] Dhai A, McQuoid-Mason D & Knapp van Bogaert D "Ethical concepts, theories and principles and their application to healthcare" in Dhai A & McQuoid-Mason D *Bioethics, Human Rights and Health Law: Principles and Practice* (2011) 12.
[72] Dhai A, McQuoid-Mason D & Knapp van Bogaert D "Ethical concepts, theories and principles and their application to healthcare" in Dhai A & McQuoid-Mason D *Bioethics, Human Rights and Health Law: Principles and Practice* (2011) 12.

Anderson argues that there might be a dilemma between endeavouring to respect patient autonomy while following the principles of *beneficence* and *non-maleficence.* The doctor has the difficult choice to either respect a patient's autonomy, which can include different actions including the withdrawal of treatment, or to follow his or her duty of care to benefit the patient (*beneficence*) and to do no harm (*non-maleficence*). Anderson argues that the advance directive might be useful in this difficult medical decision making scenario and help the doctor to decide whether to allow "medical autonomy to overrule the earlier expressed individual autonomy of the patient".[73] Anderson explains that the use of living wills and advance directives may ultimately erode the decision making power of the doctor and by doing so aggravate the conflict between professional and individual autonomy. Doctors' professional autonomy is based on their knowledge and expertise to define the needs of the patient to determine how these needs must be met. This professional autonomy is protected by the medical profession's right to self-regulation.[74]

The exercise of patient autonomy plays such an important role in medical decision making in South Africa that the practice of medicine has developed from a paternalistic model of medical decision making to one where there is a partnership between doctor and patient based on mutual decision making. For mutual decision making to work, autonomy must include concepts such as informed consent, confidentiality, truth telling and thus promote a relationship of trust between doctor and patient. Norval and Gwyther raise an important point that it is "autonomy" that allows a patient to become "an active member of the management team" which "restores a sense of control in the face of an illness that has removed control from the patient".[75]

[73] Anderson SJ *Planning for the future: a comparative study of advance directives in Scotland, England and the Netherlands* PhD University of Edinburgh (2004) 146.
[74] Anderson SJ *Planning for the future: a comparative study of advance directives in Scotland, England and the Netherlands* PhD University of Edinburgh (2004) 146.
[75] Norval D & Gwyther E "Ethical decisions in end-of-life care" 2003 *CME* 21 5 267.

1.2.3.2 Sanctity of Life versus Quality of Life

One school of thought on the sanctity of life is that life has intrinsic value and therefore assisted dying is regarded as incompatible with the sanctity of human life.[76] This idea originates from a religious perspective that should human beings choose the moment of their own death and take active steps to bring it about, it will "usurp God's monopoly upon the power to give and take life".[77] In terms of this sanctity of life view, living wills are seen as morally wrong, as no person has the right to refuse measures that will prolong life.[78] It has also been argued that modern medicine has already partially usurped God's monopoly by for example the administration of life-preserving medications such as antibiotics, or the removal of life-sustaining treatment and the administering of drugs in life-threatening dosages to relieve pain.[79]

Patients can by way of living wills indicate what standard of quality of life would be acceptable to them in specific circumstances such as being in a persistent vegetative state or suffering severe disability. Furthermore, these patients can provide directions with regard to quality of life in different circumstances, which at the very least will aid medical personnel and family to interpret a patient's directive and act thereon.

1.2.3.3 *Beneficence* and *Non-maleficence*

Dworkin explains the concept of *beneficence* as follows:

> "When one person is entrusted to the charge or care of another, the former has … a right to *beneficence* – a right that the latter make decisions in the former's best interests. This fiduciary right is a familiar idea in both law and morals: a trustee must act in the interests of the trust's beneficiaries; the directors of a

[76] Jackson E and Keown K *Debating Euthanasia* (2012) 37.
[77] Jackson E and Keown K *Debating Euthanasia* (2012) 37.
[78] Age Concern Institute of Gerontology Centre of Medical Law and Ethics *The Living will: consent to treatment at the end of life A working party report* (1988) 2.
[79] Jackson E and Keown K *Debating Euthanasia* (2012) 42.

corporation must act in the interests of its shareholders; doctors and other professionals must act in the interests of their patients or clients."[80]

In medical practice the concepts of *beneficence* (to do good for others, to promote others' interests and well-being) and non-*maleficence* (to do no harm or as little harm as possible) are closely related.[81] Beneficence requires practitioners to act "in the best interests of their patients" and to "aim at promoting their positive welfare".[82]

Any medical treatment or intervention such as the use of medication, medical procedures and surgery all carry the risk that harm may result. The risks and benefits must therefore be weighed up.

The HPCSA is a statutory body which was created in terms of the Health Professions Act[83] which is responsible for setting standards for professional and ethical conduct which health care practitioners who are registered members, should adhere to.[84]

The prescribed ethical principle of the HPCSA which holds that health care practitioners are required to undergo continuous professional development training (CPD training) to obtain "the highest skill and knowledge" for "professional competence and self-improvement", contributes to the notion of *beneficence*.[85]

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[80] Dworkin R "Life past reason" in *Life's Dominion* (1993) 228.
[81] Norval D & Gwyther E "Ethical decisions in end-of-life care" 2003 *CME* 21 5 267; Dhai A, McQuoid-Mason D & Knapp van Bogaert D "Ethical concepts, theories and principles and their application to healthcare" in Dhai A & McQuoid-Mason D *Bioethics, Human Rights and Health Law: Principles and Practice* (2011) 14.
[82] Dhai A, McQuoid-Mason D & Knapp van Bogaert D "Ethical concepts, theories and principles and their application to healthcare" in Dhai A & McQuoid-Mason D *Bioethics, Human Rights and Health Law: Principles and Practice* (2011) 14.
[83] Health Professions Act, 56 of 1974.
[84] Dhai A & Etheredge H "Codes of healthcare ethics" in Dhai A & McQuoid-Mason D *Bioethics, Human Rights and Health Law: Principles and Practice* (2011) 16.
[85] Norval D & Gwyther E "Ethical decisions in end-of-life care" 2003 *CME* 21 5 267; HPCSA "Guidelines for good practice in the healthcare professions: General ethical guidelines for the healthcare professions" Booklet 1 (September 2016) <https://www.hpcsa.co.za/Conduct/Ethics> (accessed 22-06-2019).

The primary purpose of living wills is to give effect to a patient's right to refuse or alter the course of medical treatment.[86] Some believe legislating end-of-life decisions such as living wills might impact negatively on doctor-patient relationships which can come into conflict with the principles of patient autonomy.[87] Dworkin correctly points out that the right of *beneficence* differs from the right to autonomy and may in some circumstances even come into conflict with one another.[88] One such a conflict would be between a mentally incompetent person's current best interests and, what Dworkin aptly calls his "precedent autonomy" when he was still mentally competent and issued instructions, for example, by means of a living will.[89]

The best interests of the patient in the opinion of the doctor who is bound by the Hippocratic Oath might not always be what the patient requested in the living will. The Hippocratic Oath, which states that the primary duty of the health care practitioner is to act in the patient's best interest and to avoid harm, is seen as the "most fundamental underpinning of the moral values shared by healthcare practitioners".[90] According to Carstens the Hippocratic Oath is "generally acknowledged by both physicians and lay people to be the foundation of medical ethics for physicians in the West".[91]

The Declaration of Geneva[92] and the Florence Nightingale Pledge[93] echo the principles of the Hippocratic Oath.

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[86] Age Concern Institute of Gerontology Centre of Medical Law and Ethics *The Living will: consent to treatment at the end of life A working party report* (1988) 44.
[87] Jackson E and Keown K *Debating Euthanasia* (2012) 43.
[88] Dworkin R "Life Past Reason" in *Life's Dominion* (1993) 229.
[89] Dworkin R "Life Past Reason" in *Life's Dominion* (1993) 229.
[90] Dhai A & Etheredge H "Codes of healthcare ethics" in Dhai A & McQuoid-Mason D *Bioethics, Human Rights and Health Law: Principles and Practice* (2011) 16.
[91] Carstens P "Revisiting the infamous Pernkopf Anatomy Atlas: historical lessons for medical law and ethics" *Fundamina* (2012) 18 (2) 37 fn73.
[92] World Medical Association "Declaration of Geneva" (version 2006) <https://www.wma.net/what-we-do/medical-ethics/declaration-of-geneva/> (accessed 19-07-2019).
[93] Dhai A & Etheredge H "Codes of healthcare ethics" in Dhai A & McQuoid-Mason D *Bioethics, Human Rights and Health Law: Principles and Practice* (2011) 16.

The Declaration of Geneva,[94] which is regarded as a modern day version of the Hippocratic Oath, was renamed "The Physician's Pledge" and amended in 2017 to specifically include the following wording: "I will respect the autonomy and dignity of my patient". The wording of the amended Declaration of Geneva[95], reads as follows:

"The Physician's Pledge

As a member of the medical profession:

I solemnly pledge to dedicate my life to the service of humanity;

The health and well-being of my patient will be my first consideration;

I will respect the autonomy and dignity of my patient;

I will maintain the utmost respect for human life;

I will not permit considerations of age, disease or disability, creed, ethnic origin, gender, nationality, political affiliation, race, sexual orientation, social standing or any other factor to intervene between my duty and my patient;

I will respect the secrets that are confided in me, even after the patient has died;

I will practise my profession with conscience and dignity and in accordance with good medical practice;

I will foster the honour and noble traditions of the medical profession;

I will give to my teachers, colleagues, and students the respect and gratitude that is their due;

I will share my medical knowledge for the benefit of the patient and the advancement of healthcare;

I will attend to my own health, well-being, and abilities in order to provide care of the highest standard;

I will not use my medical knowledge to violate human rights and civil liberties, even under threat;

I make these promises solemnly, freely, and upon my honour."

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[94] World Medical Association "Declaration of Geneva" (*as amended by the 68th WMA General Assembly, Chicago, United States, October 2017*) <https://www.wma.net/policies-post/wma-declaration-of-geneva/> (accessed 19-07-2019).

[95] World Medical Association "Declaration of Geneva" (*as amended by the 68th WMA General Assembly, Chicago, United States, October 2017*) <https://www.wma.net/policies-post/wma-declaration-of-geneva/> (accessed 19-07-2019).

The Florence Nightingale pledge was first taken by nurses in the United States of America in 1893 and has since been adopted by nursing professions in different jurisdictions, including South Africa. The version of the Florence Nightingale pledge as adapted and adopted by the South African Nursing Council, reads as follows:

> "Nurses' Pledge of Service
>
> I solemnly pledge myself to the service of humanity and will endeavour to practise my profession with conscience and with dignity.
>
> I will maintain, by all the means in my power, the honour and noble tradition of my profession.
>
> The total health of my patients will be my first consideration.
>
> I will hold in confidence all personal matters coming to my knowledge.
>
> I will not permit consideration of religion, nationality, race or social standing to intervene between my duty and my patient.
>
> I will maintain the utmost respect for human life.
>
> I make these promises solemnly, freely and upon my honour."[96]

These pledges contain provisions that are both challenging to the legal enforcement of living wills and supportive of the legal enforcement of living wills which will be discussed in more detail in later chapters.

1.2.3.4 Justice and Socio-Economic Factors

The principle of justice in the context of health care refers mainly to "distributive justice" and "the fair allocation of scarce healthcare resources".[97]

[96] South African Nursing Council "Nurses' Pledge" <http://www.sanc.co.za/aboutpledge.htm> (accessed 19-07-2019).

[97] Dhai A, McQuoid-Mason D & Knapp van Bogaert D "Ethical concepts, theories and principles and their application to healthcare" in Dhai A & McQuoid-Mason D *Bioethics, Human Rights and Health Law: Principles and Practice* (2011) 15.

In South Africa where many people live in rural areas or economically impoverished settlements, accessibility to health care is often a problem. Patients who cannot afford private health care, have to rely on state-funded institutions for their medical procedures and medicines. The costs of accessing health services in South Africa can be crippling for poor households.[98] It is necessary to investigate the South African health care system and its practical and managerial problems, as well as the financial constraints which it faces, in the discussion of the legal enforcement of living wills.

Norval and Gwyther explain the principle of justice and socio-economic factors as follows:

> "The principle of justice is that by which competing claims may be decided upon in fairness. This can further be decided according to distributed justice (fair distribution of resources), rights-based justice (eg all people have the right to equal health care) and legal justice (according to the country's laws). There are a number of competing claims, particularly in the SA setting, where patients in a medical aid or private health care setting have access to health care that is not afforded to patients in the public health care setting."[99]

The question therefore should be posed whether people who live in poverty and need to make use of public health care, are in a position to make advance health care decisions which will have to be enforced when they are faced with future incapacity.

1.2.4 Codes and Guidelines for Health Care Ethics

Ethical codes provide a framework and guidelines for morality in health care and health care practice by setting down norms to regulate the interactions between firstly patient and health care practitioners and secondly the interactions among health care

[98] Harris B "Inequities in access to health care in South Africa" (2011) *Journal of Public Health Policy* 32 102–123.
[99] Norval D & Gwyther E "Ethical decisions in end-of-life care" 2003 *CME* 21 5 268.

practitioners themselves.[100] In South Africa different associations and councils have published ethical guidelines which are important in the field of advance directives and living wills.

1.2.4.1 Health Professions Council of South Africa: Ethical Guidelines

The Health Professions Council of South Africa (HPCSA) has published various ethical guidelines applicable to the enforceability of living wills and advance directives. These include guidelines on informed consent, guidelines on withdrawing and withholding of treatment, and guidelines on good clinical practice.[101] The HPCSA guidelines direct that any advance refusals of treatment (living wills) should be respected. The HPCSA states that patients should be granted the opportunity and be encouraged to indicate their wishes regarding future treatment and to utilise a living will to write down their future care directives.[102] The HPCSA also encourages the patient to mandate a third party to act on his or her behalf when they are no longer able to provide their own health care instructions.

1.2.4.2 South African Medical Association Guidelines

Since there is at present no specific law regarding the validity of living wills in South Africa, the South African Medical Association ("SAMA") has published guidelines for medical practitioners on living wills and advance directives.[103] These guidelines have been implemented as policy since June 1994. SAMA has published various other guidelines pertaining to the enforceability and practicality of living wills and advance

[100] Dhai A, McQuoid-Mason D & Knapp van Bogaert D "Ethical concepts, theories and principles and their application to healthcare" in Dhai A & McQuoid-Mason D *Bioethics, Human Rights and Health Law: Principles and Practice* (2011) 16.
[101] See Chapter 3 paras 3.5.1 & 3.5.2.
[102] HPCSA "Guidelines for the withholding and withdrawing of treatment" "Booklet 7" <https://www.hpcsa .co.za/Uploads/editor/UserFiles/downloads/conduct_ethics/Booklet%207.pdf> (accessed 30-07-2019).
[103] SAMA "Guidelines for Medical Practitioners on Living Wills prepared by the South African Medical Association (Policy since June 1994)" <https://www.samedical. org/images/attachments/guidelines-with-regard-to-living-wills-2012.pdf> (accessed 30-07-2019).

directives such as euthanasia guidelines and informed consent guidelines.[104] To address the legal lacunae the South African Law Commission published a Draft Bill on End of Life Decisions, 1998.[105] Furthermore, a Private Member's Bill named the National Health Amendment Bill, 2019, was drafted.[106]

1.2.4.3 International Codes for Health Care Ethics

Various International Codes for Health Care Ethics exist which are important in the field of end-of-life decisions, living wills and advance directives. These are discussed in detail in Chapter 4.[107] One example of such a document is the Convention of Venice on Terminal Illness, 2006,[108] which provides as follows:

> "Physicians should recognise the right of patients to develop written advance directives that describe their wishes regarding care in the event that they are unable to communicate and that designate a substitute decision-maker to make decisions that are not expressed in the advance directive. In particular, physicians should discuss the patient's wishes regarding the approach to life-sustaining interventions as well as palliative measures that might have the additional effect of accelerating death. Whenever possible, the patient's substitute decision maker should be included in these conversations."[109]

[104] See further discussion in Chapter 3 paras 3.5.3 & 3.5.4. The International Ethical Codes pertaining to living wills are referred to in paragraph 1.2.4.3 below and discussed in detail in chapter 4 para 4.2.
[105] See para 1.2.5 below and Chapter 3 para 3.7.1.
[106] See para 1.2.6 below and Chapter 3 para 3.7.2.
[107] See Chapter 4 para 4.2.
[108] Convention of Venice on Terminal Illness, 2006.
[109] Principle 5 Convention of Venice on Terminal Illness adopted by the 35th World Medical Assembly, Venice, Italy, October 1983 and revised by the 57th WMA General Assembly, Pilanesberg, South Africa, October 2006.

1.2.5 Draft Bill on End of Life Decisions

The South African Law Commission's Draft Bill on End of Life Decisions regulates the enforcement of living wills.[110] Clause 6(1) determines that:

> "Every person above the age of 18 years who is of sound mind shall be competent to issue a written directive declaring that if he or she should ever suffer from a terminal illness and would as a result be unable to make or communicate decisions concerning his or her medical treatment or its cessation, medical treatment should not be instituted or any medical treatment which he or she may receive should be discontinued and that only palliative care should be administered".

It is furthermore an option for the person as contemplated in sub-clause 6(1) to act as a principal and entrust any decision making regarding the medical treatment or the cessation of such treatment to a competent agent by way of a written power of attorney.[111] This power of attorney will come into and remain in force once the principal becomes terminally ill and as a result of the illness is unable to make or communicate decisions concerning his or her medical treatment or the cessation thereof.[112] It will not be unlawful to cease medical treatment as contemplated in clause 6(1) if it contributes to causing the patient's death or hastening the moment of death.[113]

The Draft Bill on End of Life Decisions states that the living will and enduring power of attorney or any amendments to these documents should be signed by the maker in the presence of two competent witnesses.[114] These two competent witnesses are required to sign the document in the presence of the maker and in the presence of each other.[115]

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[110] Draft Bill on End of Life Decisions as contained in the South African Law Commission Report *Project 86 Euthanasia and the artificial preservation of life* (1998) hereinafter "Draft Bill on End of Life Decisions".
[111] Cl 6(2) Draft Bill on End of Life Decisions.
[112] Cl 6(2) Draft Bill on End of Life Decisions.
[113] Cl 8(4) Draft Bill on End of Life Decisions; Cl 7(6) Draft Bill on End of Life Decisions.
[114] Cl 6(3) Draft Bill on End of Life Decisions.
[115] Cl 6(3) Draft Bill on End of Life Decisions.

The Draft Bill on End of Life Decisions furthermore regulates the position of persons who are under guardianship or in cases where a curator of the person has been appointed. Should such a person become terminally ill and no instructions regarding his medical treatment or the cessation thereof have been issued, the decision making regarding such treatment or the cessation thereof shall, in the absence of any court order or the provisions of any other Act, vest in such guardian or curator.[116]

The Draft Bill on End of Life Decisions furthermore specifies the standards of conduct expected from medical practitioners in compliance with directives by or on behalf of terminally ill persons.

Clause 7(1) states that:

> "No medical practitioner shall give effect to a directive regarding the refusal or cessation of medical treatment or the administering of palliative care which may contribute to the hastening of a patient's death, unless-
> (a) the medical practitioner is satisfied that the patient concerned is suffering from a terminal illness and is therefore unable to make or communicate considered decisions concerning his or her medical treatment or the cessation thereof; and
> (b) the condition of the patient concerned, as contemplated in paragraph (a), has been confirmed by at least one other medical practitioner who is not directly involved in the treatment of the patient concerned, but who is competent to express a professional opinion on the patient's condition because of his expert knowledge of the patient's illness and his or her examination of the patient concerned."

A medical practitioner must first ascertain whether an advance directive is authentic, and whether the person who issued the directive was mentally competent when the

[116] Cl 6(4) Draft Bill on End of Life Decisions.

directive was formulated, before giving effect to an advance directive.[117] If the advance directive is found to be authentic and the maker was mentally competent at the time of drafting the advance directive, a medical practitioner should communicate the existence and content of the directive of the patient concerned, and subsequently his findings and intentions, as well as that of the other medical practitioner, to the relevant family members of the patient before giving effect to such an advance directive.[118]

Should a medical practitioner be uncertain as to the authenticity of an advance directive, or should he or she have doubts about its legality, he or she shall treat the patient concerned in accordance with the position as set out in clause 8 which prescribes the conduct of a medical practitioner in the absence of a directive.[119] Clause 8(1) determines that:[120]

> "If a medical practitioner responsible for the treatment of a patient in a hospital, clinic or similar institution where a patient is being cared for, is of the opinion that the patient is in a state of terminal illness as contemplated in this Act and unable to make or communicate decisions concerning his or her medical treatment or its cessation, and his or her opinion is confirmed in writing by at least one other medical practitioner who has not treated the person concerned as a patient, but who has examined him or her and who is competent to submit a professional opinion regarding the patient's condition on account of his or her expertise regarding the illness of the patient concerned, the first-mentioned medical practitioner may, in the absence of any directive as contemplated in clause 6(1) and (2) or a court order as contemplated in clause 9, grant written authorisation for the cessation of all further life-sustaining medical treatment and the administering of palliative care only."

[117] Cl 7(2) Draft Bill on End of Life Decisions.
[118] Cl 7(3) Draft Bill on End of Life Decisions.
[119] Cl 7(4) Draft Bill on End of Life Decisions.
[120] Cl 8(1) Draft Bill on End of Life Decisions.

Before a medical practitioner may act as contemplated in clause 8(1), he or she needs to enquire whether such conduct would be in line with the wishes of the relevant family members of the patient, except if the medical practitioner is authorised to act in accordance with clause 8(1) by means of a court order spelled out in clause 9.[121]

The Draft Bill on End of Life Decisions states that a medical practitioner is required to record in writing what his or her findings are regarding the patient's condition and any measures taken by him or her in respect of the patient's condition.[122] The Draft Bill on End of Life Decisions specifically states that the provisions contained in the Bill may not be interpreted as to "oblige a medical practitioner to do anything that would be in conflict with his or her conscience or any ethical code to which he or she feels himself or herself bound".[123]

In fact, the Draft Bill on End of Life Decisions gives radical powers to the court to terminate treatment in the absence of a directive by the patient.[124] The court may for instance order that medical treatment be stopped if there is no directive by or on behalf of a terminally ill person, and if the patient is suffering from a terminal illness and is unable to make or communicate decisions concerning his or her medical treatment or its cessation. Such an application for the cessation of medical treatment can be made by any interested party.[125] However, the court may not make this order without the knowledge of interested family members, and without their having been given the opportunity to be heard by the court.[126]

The court needs to be convinced of the medical facts that should be based on evidence of at least two medical practitioners who have expert knowledge of the patient's

[121] Cl 8(2) Draft Bill on End of Life Decisions.
[122] Cl 8(3) Draft Bill on End of Life Decisions.
[123] Cl 10 Draft Bill on End of Life Decisions.
[124] Sneiderman B & McQuoid-Mason DJ "Decision-making at the end of life: the termination of life-prolonging treatment, euthanasia (mercy-killing), and assisted suicide in Canada and South Africa" (2000) *CILSA* XXXIII 199.
[125] Cl 9(1) Draft Bill on End of Life Decisions.
[126] Cl 9(2) Draft Bill on End of Life Decisions.

condition and who have personally examined and treated the patient, or who have informed themselves of the patient's medical history and have personally examined the patient.[127] A medical practitioner who gives effect to such a court order will not incur any civil, criminal or other liability whatsoever.[128] According to Sneiderman and McQuoid-Mason these wide discretionary powers given to the court, could cause hospital administrators who try to conserve limited valuable medical resources to apply to court to have persistent vegetative state patients whose prognoses are hopeless removed from ventilators against the wishes of their families.[129] These authors are further of the opinion that as long as there is a good reason for the hospital administrators' applications, they should succeed.[130]

1.2.6 National Health Amendment Bill, 2019

The National Health Bill, 2019, a Private Member's Bill, was introduced by private member, Deidre Carter, on 27 February 2019. The National Health Amendment Bill, 2019 (Private Member's Bill) attempted to provide a legal framework for durable powers of attorney for health care and living wills. The objects of the Bill were to amend the National Health Act so that advance health care directives such as living wills and durable powers of attorney for health care could be legally recognised and to provide for "legal certainty and legal enforceability regarding these directives".[131] Unfortunately the Bill was inadequate in these respects.[132] Furthermore the Bill had unfortunately lapsed in May 2019 in terms of the rules of Parliament when the new Parliament was elected

[127] Cl 9(3) Draft Bill on End of Life Decisions.
[128] Cl 9(4) Draft Bill on End of Life Decisions.
[129] Sneiderman B & McQuoid-Mason DJ "Decision-making at the end of life: the termination of life-prolonging treatment, euthanasia (mercy-killing), and assisted suicide in Canada and South Africa" (2000) *CILSA* XXXIII 199.
[130] *Soobramoney v Minister of Health, KwaZulu-Natal* 1998 1 SA 765 (CC) in Sneiderman B & McQuoid-Mason D "Decision-making at the end of life: the termination of life-prolonging treatment, euthanasia (mercy-killing), and assisted suicide in Canada and South Africa" (2000) *CILSA* XXXIII 199.
[131] Point 2 Memorandum on the objects of the National Health Amendment Bill, 2019 attached to the National Health Amendment Bill, 2019 (Private Member's Bill).
[132] See critique in Chapters 3 para 3.7.2 and throughout Chapter 5.

after the South African general elections.[133] Mrs Carter is also no longer a Member of Parliament. We shall therefore wait to see whether a new draft of the Bill will be re-submitted to Parliament by another Member of Parliament, in future.[134]

1.2.7 South African Case Law

In the following paragraphs the most prominent South African cases and legal challenges are described pertaining to living wills and assisted suicide. To date no South African court has ruled on the legal validity of a living will document, but the court in *Clarke v Hurst*[135] has referred to the legal position of discontinuance of medical treatment in the case of a patient in a persistent vegetative state.

1.2.7.1 *Clarke v Hurst*

The 1992 *Clarke v Hurst*[136] case dealt with the dilemma of the possible withdrawal of life-prolonging treatment from a mentally incompetent patient. Dr Clarke (the patient) had suffered a heart attack which resulted in complete cessation of his breathing and heartbeat. However, his heartbeat was restored after resuscitation, but since he had been deprived of oxygen to the brain for a prolonged period, he had suffered serious and irreversible brain damage. As a result of this brain injury he remained in a comatose state, and in addition he was unable to swallow and had to receive feeding through a naso-gastric tube. Dr Clarke did have a living will which was unfortunately discovered only after he had been subjected to life-sustaining measures. This situation continued for four years after which he still remained in a persistent vegetative state. At this point in time Mrs Clarke applied to the court to be appointed as *curatrix personae* of her husband. She wished to obtain the power to authorise the discontinuation of any further

[133] The National Health Amendment Bill, 2019 (Private Member's Bill) lapsed in terms of Rule 333(2) of the National Assembly. Cruywagen V **"**New draft assisted-suicide bill delayed by the election of Parliament" (20 June 2019) *Cape Argus* 1.
[134] See Chapters 3 and 5 on the details and critique of the National Health Amendment Bill, 2018.
[135] *Clarke v Hurst NO and others* 1992 4 SA 630 (D).
[136] *Clarke v Hurst NO and others* 1992 4 SA 630 (D).

medical treatment including artificial feeding. She requested a court order declaring to the effect that she would not be acting unlawfully if she were to withhold permission to medical treatment or if she were to authorise that artificial life-sustaining measures be discontinued, even if such discontinuance would end her husband's life.

The court did not venture an opinion on the legal validity of the living will, but did however take note of Dr Clark's living will and the fact that he had previously spoken out in favour of passive euthanasia. The court subsequently stated that:

> "It is indeed difficult to appreciate a situation, save where the patient is suffering unbearable pain or is in a vegetative state, where it would be in his best interests not to exist at all. The patient in the present case has, however, passed beyond the point where he could be said to have an interest in the matter. But just as a living person has an interest in the disposal of his body, so I think the patient's wishes as expressed when he was in good health should be given effect."[137]

The court held that because the capacity of Dr Clarke's brain for cognitive and collative life had been destroyed and the destruction of this capacity was irreparable, "the brain has permanently lost the capacity to induce a physical and mental existence at a level which qualifies as human life".[138] This meant that "judged by society's legal convictions, the feeding of the patient does not serve the purpose of supporting human life as it is commonly known" and the applicant, if appointed as *curatrix,* would act reasonably and would be justified in discontinuing the artificial feeding and would therefore not be acting wrongfully if she were to do so".[139] This judgment was criticised on the point that the court did not recognise the patient's right to autonomy.[140] This criticism highlights the

[137] *Clarke v Hurst NO and others* 1992 4 SA 630 (D) at 660.
[138] *Clarke v Hurst NO and others* 1992 4 SA 630 (D) at 649.
[139] *Clarke v Hurst NO and others* 1992 4 SA 630 (D) at 649.
[140] Slabbert M & van der Westhuizen C "Death with dignity in lieu of euthanasia" (2007) 22 *SAPR/PL* 368; Strauss SA "The 'right to die' or 'passive euthanasia': two important decisions, one American and the other South African" (1993) 6 *South African Journal of Criminal Justice* 208. Cf case discussions on *Clarke v Hurst* 1992 4 SA 630 (D) in Lupton ML "Clarke v Hurst NO, Brain NO & Attorney-General, Natal" (1992) *South African Journal of Criminal Justice* 342-348 and Skeen A "Living wills and advance directives in South African Law" (2004) University of the Witwatersrand (2004) 23(4):9 *Med Law* 938-939.

moral and ethical dilemma of the law in taking decisions on matters regarding the prolonging of human life when the quality of such life is questionable.

1.2.7.2 *S v Hartmann*

In the *S v Hartmann*[141] case a medical practitioner was convicted of the murder of his father. On the facts Dr Hartmann's father was close to death and suffering from severe pain as a result of widespread cancer. There was no option of a cure. Dr Hartmann's father did not have a living will, but had told the son about his end-of-life wishes. The father died as a result of Dr Hartmann administering a lethal dose of pentothal. The court held that the accused clearly possessed the requisite intention which was an essential element of murder. Even if it could be found that the deceased had consented to the administration of the drugs, it would not constitute a defence to the charge of murder. Although this mercy killing amounted to murder, leniency was expressed in the sentence imposed. The sentence of one year's imprisonment was wholly suspended on certain conditions. The accused had to remain in custody until the rising of court.

1.2.7.3 *Stransham-Ford v Minister of Justice and Correctional Services*

In this case[142] the applicant (Mr Stransham-Ford) brought an urgent application in the Gauteng High Court in 2015 to request a declaratory order to the effect that he be allowed to request that a medical practitioner assist in ending his life; that the medical practitioner will not be held accountable, be free of any civil, criminal or disciplinary liability; and that that the common law be developed in line with the Constitution to give effect to the applicant's wishes. The applicant passed away two hours prior to the court granting the declaratory order. Fabricius, J was only made aware of the applicant's demise after he had delivered the judgment.

[141] *S v Hartmann* 1975(3) SA 532 (C).
[142] *Stransham-Ford v Minister of Justice and Correctional Services and Others* [2015] 3 All SA 109 (GP).

Therefore, in its judgment the court found that in the specific circumstances of the case, the applicant was indeed entitled to be assisted by a willing and qualified medical practitioner in ending his life. The court found that in the context of assisted suicide by medical practitioners, the common law crimes of murder or culpable homicide provide for an absolute prohibition of assisted suicide, which unjustifiably limits the applicant's constitutional rights to human dignity[143] and freedom to bodily and psychological integrity[144] and to that extent these crimes are declared to be overbroad and in conflict with the said provisions of the Bill of Rights. Furthermore the court found that the medical practitioner would not be considered to be acting unlawfully and thus not be subject to prosecution or disciplinary proceedings by the respective respondents.[145]

1.2.7.4 *Minister of Justice and Correctional Services v Estate Late Robert James Stransham-Ford*

In the Appeal case[146] the SCA upheld the appeal and set aside the order of the North Gauteng High Court on three inter-related grounds. The first ground was that Mr Stransham-Ford's claim was entirely personal to him, and when he died his claim ceased to exist, therefore the High Court did not have the requisite authority to make an order on his application. The SCA also said that when Fabricius, J's attention was drawn to the fact that Mr Stransham-Ford had died two hours prior to granting the order, he should have rescinded the order, made in error. The second ground for setting aside the order was that the High Court had proceeded from an incorrect view of the current state of the law. The SCA said that the High Court failed to distinguish between the legal implications of an order authorising a medical practitioner to administer a lethal substance to a patient with the latter's consent (euthanasia) and a medical practitioner prescribing drugs that a patient could self-administer, in an act of suicide (physician

[143] S 10 Constitution of the Republic of South Africa, 1996.
[144] S 12(2)(b) read with S 1 and S 7 Constitution of the Republic of South Africa, 1996.
[145] See case discussion in Chapter 5 para 5.10. Cf critique of Moodley K "The Fabricius decision on the Stransham-Ford case – an enlightened step in the right direction" (June 2015) 105 6 *SAMJ* 434-435.
[146] *Minister of Justice and Correctional Services and Others v Estate Late James Stransham-Ford and Others* [2017] 1 All SA 354 (SCA).

assisted suicide) which would amount to murder or culpable homicide under the current South African law. The SCA said that there was no need for the High Court to develop the common law in relation to murder and culpable homicide and any such development would have required in-depth consideration of the legal position and of international jurisprudence. The third ground that the SCA stated for setting aside the order was that the application was dealt with on an urgent basis, which in fact resulted in an inadequate record as far as the facts were concerned and the evidence before it was insufficient to develop the common law.[147]

1.2.7.5 Sean Davison: Plea and Sentencing Agreement

In this case Professor Sean Davison, the co-founder of Dignity SA, an organisation that is fighting for the legalisation of assisted suicide in South Africa, was arrested in his personal capacity on three counts of premeditated murder for assisting 3 individuals to die. According to Professor Landman, co-founder of Dignity SA, the three individuals allegedly voluntarily pleaded in three different instances, to be assisted in dying as they were all physically incapable of ending their own lives.[148] The fact that the three individuals consented to be aided in dying, is currently still not a defence to the criminal act of murder under current South African law. Davison's case was transferred to the Cape Town High Court and before the pre-trial hearing could take place, Davison entered into a plea agreement with the State in terms of which he admitted guilt and received a lesser sentence of three years' house arrest, and eight years' jail sentence suspended for five years on certain conditions. This sentence was much less than the minimum sentence as prescribed for the criminal offence of murder in terms of the Criminal Law Amendment Act.[149] The judge found compelling and extenuating

[147] See detailed discussion of the *Stransham-Ford* decisions in Chapter 5 para 5.10
[148] Landman W "Opinion: A Victim of law: The injustice of Davison murder charges" *Times Live* (24 May 2019)<https://www.google.com/amp/s/www.timeslive.co.za/amp/ideas/2019-05-24-opinion-a-victim-of-law-the-injustice-of-davison-murder-charges/> (accessed 24 May 2019).
[149] S 51(1) and Part I of Sch 2 of the Criminal Law Amendment Act, 105 of 1997. See detailed discussion on Davison's Plea and Sentencing Agreement in Chapter 5 para 5.10.

circumstances to deviate from the minimum prescribed sentence.[150] This case has led to vast media and public interest.[151]

1.2.7.6 South Gauteng High Court Application: Dieter Harck

Dieter Harck and Sue Walters have made an application to the South Gauteng High Court on a non-urgent basis for an order that they be assisted to die when facts exist and certain safeguards are met. Sue Walters has subsequently withdrawn her involvement in the court application due to ill health.

We can only hope that the High Court takes cognisance of the 2016 *Stransham-Ford* Appeal[152] decision where the Supreme Court of Appeal ("SCA") remarked:

> "When an appropriate case [not an urgent application as was the application by Stransham-Ford] comes before our courts the common law will no doubt evolve in the light of the considerations outlined there [principles already embedded in our common law and our constitutional rights] and the development in other countries."[153]

The SCA then posed the question:

> "Assuming the basis for any judgment was a finding that a constitutionally protected right had been infringed, would the more appropriate remedy be that adopted by the Canadian Supreme Court of a declaration of incompatibility [between the common law and our constitutional rights] joined with a suspension of the order to enable parliament to remedy the deficiency? That would be an extremely important possibility bearing in mind that on issues of this nature, raising complex questions of the public interest, the nature of any regulations that

[150] S 51(3)(a) of the Criminal Law Amendment Act, 105 of 1997.
[151] See Chapter 5 para 5.10 for further discussion.
[152] *Minister of Justice and Correctional Services v Estate Late James Stransham-Ford* [2017] 1 All SA 354 (SCA).
[153] My additions. *Minister of Justice and Correctional Services v Estate Late James Stransham-Ford* [2017] 1 All SA 354 (SCA) at 101.

should attach to permitted PAE [physician assisted euthanasia] or PAS [physician assisted suicide] and the supervisory regime that should accompany any relaxation of the law, the legislature is the proper engine for legal development."[154]

The above cases indicate the need for legal certainty in South Africa in so far as end-of-life decisions, advance directives and living wills are concerned. A new legal framework on living wills, will establish legal certainty, professional standards for medical personnel and reconfirm the rights of patients.[155] The discussion in paragraphs 1.1 and 1.2 above, pave the way to the research question and research aims, stated below.

1.3 Research Question

The research question of this thesis can be worded as follows: what is the current legal status of living wills in South Africa and how can legal enforcement thereof be achieved?[156]

1.4 Research Aims

The focus of this study is thus to investigate whether the current legal position in South Africa regarding living wills can be developed to give effect to the rights and wishes of patients who issued instructions by means of living wills.

It is the purpose of this thesis to achieve the following aims:

Research Aim 1:

[154] *Minister of Justice and Correctional Services v Estate Late James Stransham-Ford* [2017] 1 All SA 354 (SCA) at para 73.
[155] See Chapters 3, 5 and 6.
[156] See Chapters 3, 5 & 6.

To provide the historico-legal background to and overview of living wills in South Africa.

Research Aim 2:

To analyse the framework of relevant constitutional rights in the context of end-of-life decisions, focusing on the provisions relating to the right to life, right to dignity, right to privacy, right to equality, right to security of the person which includes the right to bodily and psychological integrity, freedom of religion, belief and opinion and the right to access to health care.

Research Aim 3:

To analyse the current draft legislation on living wills.

Research Aim 4:

To analyse how the current legal framework relates to medical, ethical, moral and philosophical issues, as well as to different socio-economic contexts in South Africa. It will be shown that legal enforceability alone is not sufficient, as the law needs to be effected within a holistic context with due consideration of the aforementioned issues.

Research Aim 5:

To analyse relevant comparative law.

This study comprises an international legal-comparative study to offer different insights and perspectives and possible solutions to the South African legal lacunae in the field of living wills and advance directives. In terms of the Constitution we can take cognisance of other legal systems for guidance on how our law needs to be developed.[157]

[157] S 39 Constitution of the Republic of South Africa, 1996.

Section 39 of the Constitution reads as follows:

"39 (1) When interpreting the Bill of Rights, a court, tribunal or forum—

(a) must promote the values that underlie an open and democratic society based on human dignity, equality and freedom;

(b) must consider international law; and

(c) may consider foreign law."

5.1 The legal position in the Netherlands will be investigated as living wills and advance directives are legally enforceable in this jurisdiction and empirical research has been done on the enforceability of living wills in this jurisdiction.

5.2 The legal position in England, where controversial advancements in the field of end-of-life decisions are debated, and advance decisions are legally recognised, will be investigated.

5.3 The legal position and new developments in the Canadian law regarding advance directives (living wills), advance requests and end-of-life decisions will be investigated.

5.4 The analyses mentioned above will serve as a foundation for drawing conclusions so as to provide a legal framework for the enforceability of living wills in South Africa.

1.5 Motivation and Problem Areas

The legal lacunae regarding living wills in South Africa cause legal uncertainty and varying enforcement standards in practice. From a medical perspective the lack of a suitable legal framework provides challenges to medical personnel who may or may not adhere to patients' wishes as stated in living wills, due to a fear of prosecution. This study will provide legal guidelines to serve as a possible framework for the enforceability of living wills in South Africa. Specific problem areas will be discussed in more detail in

chapter 5 including aspects such as do not resuscitate orders, emergency situations, permanent vegetative states, cessation of artificial hydration and feeding, pregnancy, euthanasia / assisted suicide, palliative care and pain relief, and organ donation. Another important area of concern in the context of living wills and advance directives is dementia and how and when a living will or advance directive should be interpreted in the case of a patient who suffers from dementia. The problematic aspects regarding dementia will be discussed.

1.6 Motivation of Choice of Comparative Legal Systems

The South African Constitution states that where there is need for the law to be developed, a broad approach needs to be adopted in terms of which one needs to have cognisance of other legal systems and the legal developments taking place in those jurisdictions.[158] The South African courts do in fact use this broad approach to attain legal development domestically. An international comparative study offers insights and perspectives to the South African situation which may aid the development of the law in the field of living wills and advance directives. This study therefore comprises an international legal-comparative study with the Netherlands, England and Canada. In all three of these countries much current and topical debate is taking place regarding end-of-life issues, and the advance directives that concern these end-of-life issues. Many successful, as well as unsuccessful, attempts at legal development have taken place in these chosen jurisdictions during the past few years. All these developments as well as applicability and enforceability problems arising from these ongoing legal developments in the field of end-of-life decisions in these countries offer insight, clarification, alternative perspectives and possible solutions to the South African situation.

1.6.1 The Netherlands

In the Netherlands living wills and advance directives enjoy strong legal status. Each

[158] S 39 Constitution of the Republic of South Africa, 1996.

living will *(levenstestament)* and advance directive *(wilsverklaring)* document has its own unique definitions, drafting requirements, characteristics and applicability criteria.

The *Wet op de Geneeskundige Behandelingsovereenkomst* contained in the Dutch Civil Code provides that if a person of sixteen years or older in age is no longer mentally competent, a doctor is required to honour a refusal of treatment made in writing when the patient was still competent.[159]

In the Netherlands, patients may even provide a written euthanasia directive in their living wills or advance directive to request euthanasia in advance in the specified circumstances mentioned in the euthanasia directive. Euthanasia is only legal in limited circumstances as determined in the Termination of Life and Assisted Suicide (Review Procedures) Act.[160] The euthanasia declaration must meet certain listed due care criteria.[161] The euthanasia declaration must be in the patient's handwriting and at least two physicians, the second being independent to the first physician, have to agree that the patient is terminally ill and that no hope for recovery exists.[162] If the patient aged sixteen years or older is no longer capable of expressing his will, but prior to reaching this condition was deemed to have a reasonable understanding of his interests and has made a written statement containing a request for termination of life, the physician may carry out this request. In a landmark judgment on 11 September 2019 the Den Haag court found that a physician who carried out a request for euthanasia based on the patient's advance directive did not act unlawfully. The patient was severely demented and was not in a position to reconfirm her request for euthanasia.[163]

[159] Article 450(3) *Wet op Geneeskundige Behandelingsovereenkomst* (Wet 1994-11-17 Stb 1994 837 tot wijziging van het Burgerlijk Wetboek) <www.rbng.nl/file/wettenWGBO> (accessed 21-07-15).
[160] Termination of Life and Assisted Suicide (Review Procedures) Act, 2001.
[161] Art 2(1) and art 2(2) Termination of Life and Assisted Suicide (Review Procedures) Act, 2001.
[162] Art 2(1) and art 2(2) Termination of Life and Assisted Suicide (Review Procedures) Act, 2001.
[163] Rechtbank Den Haag Zaaknummer 09/837356-18. See case discussion in Chapter 4 para 4.3.1.2.2.

1.6.2 England

Under the English common law living wills were recognised as valid and enforceable.[164] Since 2007 when the English Mental Capacity Act[165] came into force, it has become possible to make an advance decision in terms of the Mental Capacity Act or appoint a health care proxy in terms of a lasting power of attorney. This advance refusal of treatment only becomes relevant once the person starts to lack mental capacity. The advance decision must be made by a competent person over the age of 18 and worded in specific words with reference to the treatment that is being refused as well as the circumstances to which the refusal will apply.[166] If the patient is an adult, was competent and properly informed when reaching the decision, and said decision is clearly applicable to the present circumstances and there is no reason to believe that circumstances exist which the patient did not anticipate at the time when the advance decision was made and which would have affected his or her decision had he or she anticipated them, then the advance decision is legally binding.[167]

There is no specific prescribed statutory form required for the validity of an advance decision. The advance decision must be in writing and signed by the patient or by another person in the patient's presence and on the patient's direction where it amounts to a refusal of life-sustaining treatment.[168] The act also provides for the appointment of a health care proxy by means of a lasting power of attorney through which persons may appoint someone else to make health care decisions on their behalf, should they lose the capacity to decide for themselves.[169]

In 2007 the British Government created the "Office of the Public Guardian". This office is there to protect people in England and Wales who may not have the mental capacity to

[164] Jordaan L "The legal validity of an advance refusal of medical treatment in South African law" (Part 2) (2011) *De Jure* 266.
[165] Mental Capacity Act, 2005.
[166] S 24(1) Mental Capacity Act, 2005.
[167] S 25 Mental Capacity Act, 2005.
[168] S 25(6) Mental Capacity Act, 2005.
[169] S 25(2)(b) Mental Capacity Act, 2005.

make certain decisions for themselves, relating to their health and finance. This office also supports and promotes decision making for people within the framework of the Mental Capacity Act.[170]

Furthermore the British Department of Constitutional Affairs has published the Mental Capacity Act, 2005 Code of Practice which aims to provide "practical guidance" on a day-to-day basis and provide "examples of best practice to carers and practitioners".[171] This practical Code of Practice forms part of the current study.[172]

Important cases have taken place in England such as *Pretty v United Kingdom*[173] case in which the European Court of Human Rights (as the court of final instance) had to give judgment on whether the applicant who was suffering from motor neuron disease and paralysed from the neck down could receive confirmation from the Director of Public Prosecutions that should her husband assist her with suicide, he would not be prosecuted.[174]

In *R (Purdy) v Director of Public Prosecutions* case[175] the House of Lords found that Debbie Purdy, a multiple sclerosis patient, successfully argued that it is a breach of her human rights not to know whether her husband will be prosecuted if he accompanies her to the Swiss euthanasia clinic Dignitas.[176]

In the *Nicklinson* case[177] a patient suffering from locked-in syndrome, approached the High Court for a declaratory order that either the provision of medical assistance to end his life would not be unlawful because the third party would be able to rely on the

[170] Jordaan L "The legal validity of an advance refusal of medical treatment in South African law (Part 2) (2011) *De Jure* 267; "Office of the Public Guardian" <https://www.gov.uk/government/organisations/office-of-the-public-guardian> (accessed 29-7-2019).
[171] As per Lord Falconer in the Foreword of the Mental Capacity Act Code of Practice.
[172] See Chapter 4 para 4.4.3.2.
[173] *R (Pretty) v DPP* [2002] 1 AC 800; *Pretty v UK* [2002] 35 EHRR 1.
[174] See Chapter 4 para 4.4.5.2.2.1 for a discussion of this case.
[175] *R (Purdy) v Director of Public Prosecutions* [2009] UKHL 45, [2010] 1 AC 345
[176] See Chapter 4 para 4.4.5.2.2.2 for a discussion on this case.
[177] *Nicklinson R (on the application of) v Ministry of Justice* [2012] EWHC; *Nicklinson & Lamb v United Kingdom* 2478/15 [2015] ECHR 709.

common law defence of necessity for justification; or that the law on murder and assisted suicide was in breach of certain rights under the European Convention on Human Rights.[178]

The Noel Conway assisted suicide case also attracted a great deal of media attention. Conway applied for judicial review of the ban on assisted suicide.[179] Conway was 67 years of age at the time of the application, and continues to suffer from motor neuron disease. Conway argued that the ban on assisted suicide prevented him from ending his own life without protracted pain. Conway wanted to have the opportunity to be granted control over his death and doctor to be allowed to grant him a prescription of a lethal medicine to take once it was deemed that he had less than six months left to live. Conway was unsuccessful in his appeals to the High Court and Supreme Court of Appeal.[180]

The most recent challenge to decriminalise assisted dying in England was brought by Phil Newby, a 48-year-old man who suffers from motor neuron disease. We await to see the outcome of his case.[181]

On 11 September 2015 the House of Commons in a majority vote rejected a private member's Assisted Dying Bill.[182] The Bill was brought by Rob Harris. The aim of the Bill, originally put forward by Lord Falconer, was to ensure a framework to give terminally ill individuals choice over their end-of-life care by for example legalising voluntary

[178] See Chapter 4 para 4.4.5.2.2.3 for the complete case discussion.
[179] In *R (on the application of Conway) v Secretary of State for Justice* [2018] EWCA Civ 1431. See case discussion in Chapter 4 para 4.4.5.2.2.4.
[180] See case discussion Chapter 4 para 4.4. Bowcott O "Terminally ill former lecturer challenges UK ban on assisted dying" (21 March 2017) <https://www.theguardian.com/society/2017/mar/21/terminally-ill-former-lecturer-challenges-uk-ban-on-assisted-dying> (accessed 27-08-2019) ; BBC News "Terminally ill Noel Conway loses Supreme Court appeal" (27 November 2018) <https://www.bbc.com/news/uk-england-shropshire-46359845> (accessed 19-07-2019).
[181] Dying in Dignity "Terminally ill man Phil Newby launches new assisted dying case" (2 July 2019) <https://www.dignityindying.org.uk/news/terminally-ill-man-phil-newby-launches-new-assisted-dying-case/> (accessed 3-7-2019).
[182] Gallagher J & Roxby P "Assisted Dying Bill: MPs reject 'right to die' law" (11 September 2015) <http://www.bbc.com/news/health-34208624> (accessed 27-08-2019).

euthanasia.[183] 118 Members voted for the Bill and 330 voted against the Bill. One would have thought that the great margin suggested that the Bill would not be debated soon. However the latest poll instructed by campaigning group Dignity in Dying, found that two thirds of the conservative party members wanted assisted dying to be legalised.[184] The parliament debated the legal position on assisted suicide on 4 July 2019. The Member of Parliament who led the debate was Nick Boles. Boles co-chairs the All-Party Parliamentary Group on Assisted Dying. The debate considered the functioning of the current law with reference to assisted dying and focussed on how the law could be improved. [185]

Interestingly, Mr Boles admitted that he had previously been opposed to dying but his personal illness and his father's "good death" at the age of 88, made him change his mind. Boles told the media: "All we want is to give people with terminal illnesses a choice at the end of their lives. What right do people who don't want to make that choice have to deny it to others who are suffering?"[186]

The current legal situation pertaining to assisted suicide in England is very unsatisfactory, as either the Courts or Parliament still have to move to decriminalise assisted suicide.[187] Perhaps the Canadian situation, where the Supreme Court has ruled that the law criminalising assisted suicide breached human rights, is a possible solution.[188]

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[183] See discussion on the Assisted Dying Bill in Chapter 4 para 4.4.5.2.3.
[184] "Tory members back assisted dying law reform" *The Times* (4 June 2019) <https: //www.thetimes.co.uk/article/tory-members-back-assisted-dying-law-reform-zh9qs9560> (accessed 5-6-2019).
[185] Greenwood D "Stamford MP Nick Boles in push for law change on 'assisted dying'"*Rutland & Stamford Mercury* (2 July 2019) <https://www.stamfordmercury.co.uk/news/stamford-mp-nick-boles-leads-parliamentary-push-on-assisted-dying-9075172/> (accessed 3-07-2019).
[186] Greenwood D "Stamford MP Nick Boles in push for law change on 'assisted dying'"*Rutland & Stamford Mercury* (2 July 2019) < https://www.stamfordmercury.co.uk/news/stamford-mp-nick-boles-leads-parliamentary-push-on-assisted-dying-9075172/> (accessed 3-07-2019).
[187] This thesis covers the legal situation up until 11 September 2019.
[188] See Chapter 4 paras 4.5.3.1.3 & 4.5.5.2.

1.6.3 Canada

Living wills (also referred to as advance directives) and proxy directives are valid under Canadian law. However, the scope of the Provincial statutes varies in the different Provinces.[189]

The most recent landmark case on end-of-life decisions is the *Carter v Canada*[190] judgment which opens as follows:

> "It is a crime in Canada to assist another person in ending his own life. As a result, people who are grievously or irremediably ill cannot seek a physician's assistance in dying and may be condemned to a life of intolerable suffering. A person facing this prospect has two options: she can take her own life prematurely, often by violent or dangerous means, or she can suffer until she dies from natural causes. The choice is cruel."[191]

In the *Carter v Canada*[192] case, the Supreme Court of Canada had to determine whether the criminal prohibition on assisted suicide violates the rights contained in section 7 of the *Charter* namely the rights to life, liberty and security of the person[193] of competent adults who are suffering intolerably as a result of a grievous and irremediable medical condition, and to equal treatment by and under the law[194]. The court was thus requested to balance on the one hand the autonomy and dignity of a competent adult who seeks death in response to a grievous and irremediable medical condition and on the other hand the sanctity of life and the need to protect the vulnerable. Section 7 of the Charter reads as follows:

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[189] Jordaan L "The legal validity of an advance refusal of medical treatment in South African law (Part 2)" (2011) *De Jure* 265.
[190] *Carter v Canada* 2015 SCC 5.
[191] *Carter v Canada* 2015 SCC 5 par 1.
[192] *Carter v Canada* 2015 SCC 5.
[193] S 7 Canadian Charter of Rights and Freedoms.
[194] S 15 Canadian Charter of Rights and Freedoms.

> "Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice".[195]

The Court found that sections 241(*b*) and 14 of the *Criminal Code* unjustifiably infringe section 7 of the *Charter* and are of no force or effect to the extent that they prohibit physician assisted death for a competent adult person who firstly clearly consents to the termination of life and secondly has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition. The Court concluded that individuals who meet rigorous criteria should be able to avail themselves of assistance in dying.

The Supreme Court issued a 12 month suspended declaration of invalidity (until 6 February 2016 which was subsequently extended by another 4 months) to allow Parliament and the provincial legislatures to enact appropriate legislation. On 17 June 2016 the Canadian federal government gave royal assent to the country's assisted dying law namely Bill C-14. In terms of Bill C-14, which became known as the Medical Assistance in Dying Act ("MAID act"), two types of medical assistance in dying are allowed.[196] There are however problematic aspects to the applicability criteria and safeguards worked into Bill C-14 which have led to a great deal of legal research and legal challenges to find solutions to aspects where current legislation is insufficient or too narrow in application.[197]

This *Carter* case received great emphasis in the South African *Stransham-Ford* decision and is an important decision for discussion in this thesis. The fact that the drafters of the

[195] S 7 Canadian Charter of Rights and Freedoms.
[196] See discussion in Chapter 4 para 4.5.3.1.3. Austen I "Justin Trudeau Seeks to Legalize Assisted Suicide in Canada" (14 April 2016) *The New York Times* <http://www.nytimes.com/2016/04/15/world/americas/canadian-prime-minister-seeks-to-legalize-physician-assistedsuicide.html?_r=0> (accessed 22-09-2019).
[197] See Chapter 4 para 4.5.5.2.

South African Bill of Rights[198] largely based its wording on the Canadian Charter of Rights and Freedoms[199] makes Canada an important country for comparison in rights-based comparative analyses, such as the right to assisted dying.

1.7 Methodology

The first chapter sets the background to the study. An analysis of relevant constitutional rights will follow, focusing on the provisions of the right to life, right to dignity, right to privacy, right to equality, right to security of the person which includes the right to bodily and psychological integrity, freedom of religion, belief and opinion and right to access to health care. The hypothesis that a right to life includes a right to death will be debated. Thereafter the focus of the investigation will be an analysis of the historical and legal development of living wills, first locally then internationally. The South African legal framework governing living wills will be investigated with a focus on the lack of relevant common law rules, the insufficient jurisprudence and the inadequate provisions in the *Draft Bill on the Rights of the Terminally Ill* of 1997. The notion of palliative care and the doctrine of double effect will also be scrutinised.

The legal analyses mentioned above can however not be conducted in isolation, since vital contributing factors such as medical and ethical issues, moral, philosophical and socio-economic hurdles in the South African context, must be taken into account. Thus a holistic perspective will need to be employed.

An analysis of relevant comparative law will follow. The legal framework in the Netherlands will be analysed to determine to what extent the legal position in the Netherlands can contribute to resolve legal uncertainties in South Africa. The legal framework in England, as well as the current debate on living wills, will also be analysed. The legal framework in Canada will be investigated since it may also hold valuable lessons for legal enforceability of living wills in the South African context.

[198] As contained in the Constitution of the Republic of South Africa, 1996.
[199] As contained in the Constitution Act, 1982.

Ultimately, possible amendments to the current legal framework regarding living wills will be discussed to facilitate the legal enforcement of living wills in the South African context. Again it will be shown that a holistic approach needs to be employed.

1.8 Parameters and Limitations of the Study

The study focuses on the legal aspects of the enforceability of advance directives and living wills. The study promotes alternative possibilities to the currently inadequate and limited South African legal framework. The arguments proposed are rooted in all the current sources of law pertaining to this subject including common law, legislation, international law, ethical guidelines, opinion pieces, scholarly articles and other legal comparative study materials. The study will not include medical scientific research and analysis. However, relevant medico-legal ethical issues will be focussed upon. When discussing the specific issues in chapter 5, the law as it is at present will be discussed.[200] Due to the limited scope of the study the specific issues raised in chapter 5 which require in-depth analysis such as the right to euthanasia or assisted suicide will not be debated on moral grounds. The focus will be on the legality of these contentious issues. References in the text and footnotes reflect the available and accessible South African, Dutch, English and Canadian reported case law, published literature and media publications until 11 September 2019.

1.9 Programme of Study

The following chapter outlines represent the logical and systematic organisation of the investigation:

Chapter 1: Introduction

[200] Legal positions as at 11 September 2019.

This chapter commences with a description of the background and problem areas which will be addressed in this study. The motivation for this study follows. The primary research question, research aims, as well as problem areas and parameters of the investigation are discussed. This chapter contains a description of the methodology that will be employed in the thesis and the choice of legal systems is discussed. The chapter concludes with a broad overview of the programme of study and chapter descriptions.

Chapter 2: The South African Constitutional Rights with reference to End-of-life Decisions and Living Wills

This chapter will present a discussion on the relevant constitutional rights regarding end-of-life decisions, focusing on the provisions pertaining to the right to life, right to dignity, right to privacy, right to equality, right to security of the person which includes the right to bodily and psychological integrity, freedom of religion, belief and opinion and right to access to health care.

Chapter 3: The Current Legal Status of the Enforceability of Living Wills in South Africa

This chapter will focus on the historical background and current debate regarding living wills in South Africa. The current draft legislation, medical association guidelines and guidelines of the erstwhile Living Will Society will be explored.

Chapter 4: International and Comparative law: Netherlands, England and Canada

This chapter will focus on the applicable International law and international instruments as well as legal and historical background of living wills, current legal debate and legal frameworks in the selected countries namely the Netherlands, England, and Canada.

Chapter 5: The Drafting of Living Wills and the Current Status of Legal Enforceability and Applicability of Living Wills in South Africa as they relate to specific circumstances

This chapter will focus on the drafting of living wills to enhance the legal enforceability and applicability of living wills in specific circumstances. The current South African legal debate, health care guidelines, legislation and case law pertaining to these specific circumstances will be analysed. International legislation and case law from the Netherlands, England and Canada pertaining to these specific circumstances and in aid of addressing the legal lacunae that exist under the South African law, will be investigated. The focus will be on the following specific circumstances: do not resuscitate orders, emergency situations, permanent vegetative states, dementia, cessation of artificial hydration and feeding, pregnancy, euthanasia, palliative care and pain relief and organ donation. In this chapter the researcher's proposed guidelines for the legal enforceability of living wills in South Africa will be discussed. Reference will be made to the conclusions and shortcomings identified in South Africa's legal framework as discussed in chapters 2 and 3. The practical implications of these guidelines will also be mentioned. These guidelines will pose specific new challenges to the health care and legal system. Formal requirements of living wills will be elaborated on. It will also be shown that a holistic approach needs to be adopted as the law and theory and practice should serve the best interests of the patient in totality and protect his or her constitutional rights, in particular the right to autonomy in the present and future, when he or she may become incapacitated.

Chapter 6: Conclusions

In this chapter conclusions of the investigation will be given with particular reference to legal guidelines for promoting the enforceability of living wills in South Africa.

CHAPTER 2:
THE SOUTH AFRICAN CONSTITUTIONAL RIGHTS WITH REFERENCE TO END-OF-LIFE DECISIONS AND LIVING WILLS

Outline

2.1 Introduction

The legal enforcement of living wills entails the promotion and protection of certain fundamental human rights. This chapter will present a discussion of constitutional rights most relevant to the field of end-of-life decisions in general and living wills specifically. The focus will be on the constitutional provisions pertaining to the right to life, right to dignity, right to privacy, right to equality, right to freedom and security of the person which includes the right to bodily and psychological integrity, the right to freedom of religion, belief and opinion and the right to access to health care. These rights will be analysed to ultimately determine which rights should be given more weight in the context of end-of-life decisions, in light of the so-called “limitations clause” contained in

the Constitution and the purposive approach followed in interpretation of rights contained in the Bill of Rights.

Since the drafters of the South African Constitution encompassing the Bill of Rights largely based their work on the Canadian Constitution containing the Canadian Charter of Rights and Freedoms (hereinafter "the Canadian Charter"), relevant sections of the Canadian Constitution will be referred to in the course of this chapter.[201]

2.2. The Health Care System in South Africa

The South African health system comprises public and private health care sectors.[202] South Africa does not currently have a system of national or social health insurance, but Parliament is currently deliberating on whether the state should introduce a National Health Insurance scheme.[203] Currently, the great majority of South Africans receive medical care within the framework of the public health sector. People who are in the fortunate position and can either afford private medical care, or belong to a medical aid scheme as part of their workplace benefits, are able to obtain medical care from private doctors, hospitals, clinics, pharmacies and other health care providers.[204]

In terms of the South African law the doctor and patient relationship was traditionally governed by private law.[205] However, the traditional doctor-patient relationship has changed over time and is now found to be governed by public law. The reasons for the move from private to public are a result of the new Constitutional order which began with the inception of the Constitution of South Africa in 1996, as well as other relevant

[201] Currie I and De Waal J *The Bill of Rights Handbook* (2013) 152. See discussion on Canadian law regarding living wills and advance directives in Chapter 4 para 4.5.
[202] Carstens P & Pearmain D *Foundational Principles of South African Medical Law* (2007) 229.
[203] For further discussion and to see the Parliamentary developments pertaining to the National Health Insurance Bill see "National Department of Health" "NHI" <http://www.health.gov.za/index.php/nhi> (accessed 16-07-2019).
[204] See Pearmain D *The Law of Medical Schemes in SA* (2008).
[205] Carstens P & Pearmain D *Foundational Principles of South African Medical Law* (2007) 283.

national legislation such as the National Health Act[206] and the reality of the health care situation in South Africa which is such that the vast majority of South African citizens require health services delivered by the public sector.[207] According to the National Health Act,[208] the "national health system" is defined as the "system within the Republic, whether within public or private sector, in which individuals are responsible for the financing, provisions and delivery of health services". Ultimately all health care legislation has to be in line with the Constitution as the supreme law of South Africa. The Constitution protects the human rights of all citizens, also in the context of health.

2.3 The Constitution[209]

Although the South African Constitution (which contains the Bill of Rights) already has a significant impact on the field of living wills and end-of-life decisions, it is believed that it will in future have an even greater impact on legal development in this field.

2.3.1 The Interpretation of the Constitution

In the first place the Constitution's impact is greatly felt and seen in the workings of our legal system due to it being South Africa's supreme law. Furthermore, the Bill of Rights "applies to all law and binds the legislature, the executive, the judiciary and all organs of state".[210] The Bill of Rights not only offers protection to individuals against state abuse, but in addition it also offers direct protection of individuals against abuses by other individuals through the direct horizontal application of the Bill of Rights.[211] In other words the Bill of Rights has both a vertical operation and a horizontal operation. It has vertical operation, because it applies to the relationship between the state and its subjects, and it has horizontal operation, since it also applies to the relationship

[206] The National Health Act, 61 of 2003
[207] Carstens P & Pearmain D *Foundational Principles of South African Medical Law* (2007) 283.
[208] The National Health Act, 61 of 2003.
[209] Constitution of the Republic of South Africa, 1996.
[210] S 8(1) Constitution of the Republic of South Africa, 1996.
[211] Currie I and De Waal J *The Bill of Rights Handbook* (2013) 41.

between private individuals. The Bill of Rights not only has direct application, but also indirect application through the effect it has on the interpretation of our law.[212] In *Carmichele v Minister of Safety and Security*[213] the court said that the Constitution is not merely a formal document relating to public power, but an objective "normative value system" as described by Currie and De Waal, being in essence a set of values that must be respected when common law or legislation is interpreted, developed or applied.[214] However, indirect application must be considered before direct application, owing to the principle in the South African law that constitutional issues should be avoided where possible.[215] Therefore to resolve a dispute, the general legal principles as developed and interpreted in terms of the Bill of Rights must first be used before applying the Bill of Rights directly to a specific dispute.

Section 39(2) of the South African Constitution provides that:

> "When interpreting any legislation, and when developing the common law or customary law, every Court, tribunal or forum must promote the spirit, purport and objects of the Bill of Rights."

When interpreting the Bill of Rights itself, section 39(1) provides that:

> "When interpreting the Bill of Rights, a Court, tribunal or forum –
> (a) must promote the values that underlie an open and democratic society based on human dignity, equality and freedom
> (b) must consider international law; and
> (c) may consider foreign law."[216]

This thesis includes a legal comparative study in line with section 39(1).[217]

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[212] S 39(2) Constitution of the Republic of South Africa, 1996.
[213] *Carmichele v Minister of Safety and Security* 2001 (4) SA 938 (CC) at para 54.
[214] Currie I and De Waal J *The Bill of Rights Handbook* (2013) 31.
[215] *National Coalition for Gay and Lesbian Equality v Minister of Home Affairs* 2000 (2) SA 1 (CC) at 21.
[216] S 39(1) Constitution of the Republic of South Africa, 1996.
[217] See Chapter 4 "International and Comparative Law: Netherlands, England and Canada".

In the *S v Makwanyane*[218] case the Constitutional Court referring to the interpretation of the Bill of Rights said that due regard must be given to the language that has been used and a generous, purposive interpretation that gives expression to the underlying values of the Constitution, must be employed.[219]

The purposive approach entails that a provision must be interpreted to best support and protect the founding values of the Constitution, specifically the "fundamental rights in an open and democratic society based on human dignity, equality and freedom".[220] In terms of the purposive approach, once the purpose of a right in the Bill of Rights has been identified, then the scope of the right is determined.

South Africa's dark political Apartheid history, in which many human rights violations took place, also needs to be considered in the interpretation of the Constitution. When the purposive interpretation is employed, the South African history and desire for the gross human rights violations not to be repeated ever again, have to be taken into account. The Constitutional Court said that:

> "What is perfectly clear from these provisions of the Constitution and the tenor and spirit of the Constitution viewed historically and teleologically, is that the Constitution is not simply some kind of statutory codification of an acceptable or legitimate past. It retains from the past only what is defensible and represents a radical and decisive break from that part of the past which is unacceptable. It constitutes a decisive break from a culture of Apartheid and racism to a constitutionally protected culture of openness and democracy and universal human rights for South Africans of all ages, classes and colours. There is a stark and dramatic contrast between the past in which South Africans were trapped and the future on which the Constitution is premised. The past was pervaded by inequality, authoritarianism and repression. The aspiration of the future is based on what is "justifiable in an open and democratic society based on freedom and

[218] *S v Makwanyane* 1995 (3) SA 391 (CC).
[219] *S v Makwanyane* 1995 (3) SA 391 (CC) at paras 9 & 325.
[220] S 1 Constitution of the Republic of South Africa, 1996.

equality". It is premised on a legal culture of accountability and transparency. The relevant provisions of the Constitution must therefore be interpreted so as to give effect to the purposes sought to be advanced by their enactment."[221]

Furthermore, any legislation that is irreconcilable with the Constitution is invalid to the extent of the conflict. Section 39(3) states that:

> "The Bill of Rights does not deny the existence of any other rights or freedoms that are recognised or conferred by common law, customary law or legislation, to the extent that they are consistent with the Bill."[222]

However, should a court determine that a law infringes on a fundamental human right, then the court must determine whether the infringement was nevertheless reasonable and a justifiable limitation of the specific right in terms of section 36. The limitation clause indicates that rights entrenched in the Constitution are not absolute and can be limited in terms of the section 36 test.

Section 36 of the Bill of Rights on the limitation of rights determines that:

> "(1) The rights in the Bill of Rights may be limited only in terms of law of general application to the extent that the limitation is reasonable and justifiable in an open and democratic society based on human dignity, equality and freedom, taking into account all relevant factors, including-
>
> (a) the nature of the right;
>
> (b) the importance of the purpose of the limitation;
>
> (c) the nature and extent of the limitation;
>
> (d) the relation between the limitation and its purpose; and
>
> (e) less restrictive means to achieve the purpose.
>
> (2) Except as provided in subsection (1) or in any other provision of the Constitution, no law may limit any right entrenched in the Bill of Rights."

[221] *Shabalala v Attorney General of the Transvaal* 1996 (1) SA 725 (CC) at 26.
[222] S 39(3) Constitution of the Republic of South Africa, 1996.

Currie and De Waal explain that the word "limitation" used in Section 36 can be regarded as a synonym for "infringement" or "justifiable infringement" because when a law limits a right, it is said to infringe the right.[223]

Even though the South African Constitution's limitation clause follows the Canadian Constitution's limitation clause in broad terms, the South African clause is more detailed.[224]

Currie and De Waal explain that where it has been determined that a law of general application is indeed infringing on a right protected by the Bill of Rights, the State or person relying on the law may argue that the infringement constitutes a legitimate limitation of that right.[225] Furthermore rights are not absolute, therefore a right may be infringed, but only when there is a "compelling good reason" for it.[226] A "compelling good reason" would be where the infringement "serves a purpose that is considered legitimate by all reasonable citizens in a constitutional democracy that values human dignity, equality and freedom above all other considerations".[227]

Many human rights, which are contained in the Constitution, and applicable to the field of living wills and end-of-life decisions, relate to the protection of personality rights such as the right to life, dignity, privacy, freedom of security of the person which includes the right to bodily and psychological integrity as well as the right to freedom of religion, belief and opinion. However, the right to equality and right to access to health care, which are also applicable to this field, are "not directly identified as aspects of the human personality" and therefore not regarded as personality rights.[228] The most

[223] Currie I and De Waal J *The Bill of Rights Handbook* (2013) 151.
[224] Ackermann L *Human Dignity: Lodestar for Equality in South Africa* (2012) 8. See discussion on the Canadian limitations clause in Chapter 4 para 4.5.
[225] Currie I and De Waal J *The Bill of Rights Handbook* (2013) 171.
[226] Currie I and De Waal J *The Bill of Rights Handbook* (2013) 172.
[227] Currie I and De Waal J *The Bill of Rights Handbook* (2013) 172.
[228] Neethling J, Potgieter JM & Visser PJ *Neethling's Law of Personality* (2005) 17.

important human rights applicable to living wills and end-of-life decisions as protected in the Bill of Rights and their possible limitations are discussed below.[229]

2.3.2 The Right to Life

According to Neethling, Potgieter and Visser: "The bodily or physical aspect of a human being (comprising his physical-mental integrity) is, of necessity, the legal object most intimately connected with his personality. As such it forms an inseparable part of any human being and may be regarded as the most valuable interest he possesses".[230]

According to Strauss: "… the hallmark of Western civilization … is the respect for life. It is reflected in the constitutions and legal codes of our culture, in the programmes for social betterment and in the spectacular advances in medicine in our century".[231]

The modern day Hippocratic Oath, which is found in the Declaration of Geneva states *inter alia* that a doctor pledges that: "The health and life of my patient will be my first consideration".[232]

According to Strauss:

> "today there is a strong support for the notion that the individual has a qualified 'right to die'. True, our common law does not recognise the principle that the individual is *dominus membrorum suorum* (owner of his own bodily members), but it certainly recognises the principle that a person who is capable of validly expressing his will, may refuse medical treatment. Even where such an expression of a will is no longer possible, those who are 'totally disabled, long

[229] It is not appropriate in this work to embark on an in-depth discussion of all or a majority of rights in the Bill of Rights, the rights are confined to relevance in end-of-life decisions, and living wills or advance directives.
[230] Neethling J, Potgieter JM & Visser PJ *Neethling's Law of Personality* (2005) 25.
[231] Strauss SA *Doctor, patient and the law* (2001) 336.
[232] World Medical Association "Declaration of Geneva" "The physician's pledge" (as amended by the 68th WMA General Assembly, Chicago, United States, October 2017) <https://www.wma.net/policies-post/wma-declaration-of-geneva/> (accessed 19-07-2019).

> defeated, dying and already dead' … ought to be allowed, without further medical aid – however well intended – to take the final step into eternity".[233]

According to Neethling, Potgieter and Visser the right to life may be described as "the right to keep your body alive" and includes "power of disposal, or autonomy of, the individual over his (living) body in terms of the right to physical integrity (life)".[234] In *Castell v De Greef*[235] the court recognised an individual's "fundamental right to self-determination" with reference to physical integrity.[236] This right to control over your body is entrenched in S 12(2)(b) of the Constitution which reads:

> "Everyone has the right to bodily and psychological integrity, which includes the right to security in and control over their body."[237]

In the *Stransham-Ford*[238] case the Supreme Court of Appeal discussed the right to life in the context of physician assisted suicide.[239] The SCA stated that in England the House of Lords found in the *Pretty*[240] decision that the right to life, was the "antithesis of the right to determine the manner and timing of one's death". In the *Pretty*[241] appeal decision the European Court of Human Rights confirmed this finding of the House of Lords. Therefore both the House of Lords and European Court of Justice found that the right to life does not encompass a right to die, or a right to physician assisted suicide or a right to physician assisted euthanasia. The *Stransham-Ford*[242] decision focused on the European Court of Human Rights' decision in which it was held that the right to

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[233] Strauss SA *Doctor, patient and the law* (1991) 328.
[234] Neethling J, Potgieter JM & Visser PJ *Neethling's Law of Personality* (2005) fn 26 278.
[235] *Castell v De Greef* 1994 4 SA 408 (C) 420-421.
[236] *Castell v De Greef* 1994 4 SA 408 (C) 420-421. Cf Nienaber A & Bailey KN "The right to physical integrity and informed refusal: Just how far does a patient's right to refuse medical treatment go?" (November 2016) 9 2 *The South African Journal of Bioethics and Law* 73-75.
[237] S 12(2)(b) Constitution of the Republic of South Africa, 1996.
[238] *Minister of Justice and Correctional Services v Estate Late James Stransham-Ford* [2017] 1 All SA 354 (SCA).
[239] *Minister of Justice and Correctional Services v Estate Late James Stransham-Ford* [2017] 1 All SA 354 (SCA) at 62-67.
[240] *Pretty v Director of Public Prosecutions and Secretary of State for the Home Department* [2001] UKHL 61; [2002] 1 All ER (HL).
[241] *Pretty v United Kingdom* [2002] 35 EHRR at 37-42.
[242] *Minister of Justice and Correctional Services v Estate Late James Stransham-Ford* [2017] 1 All SA 354 (SCA).

decide “by what means” and at “what point” life will end, was an aspect of the right to private life.

The protection of human life and quality of life are two important concepts in the field of living wills and end-of-life decisions. Without life, the other rights in the Bill of Rights would be meaningless. Section 11 of the South African Constitution states that: “Everyone has the right to life”.[243] The right to life is thus of an unqualified nature and given strong protection in our Constitution.[244] The right to life however only attaches to “persons” recognised as such in terms of the South African Law of Persons. In terms of South African law a foetus is for example not regarded as a juristic person and therefore does not enjoy a right to life.[245]

It is trite law that the right to life is more than a right to mere physical existence. The right to life also entails a life that has human dignity. In the *S v Makwanyane*[246] case which dealt with the constitutionality of the death penalty, O’ Regan J said that:

> “The right to life is, in one sense, antecedent to all the other rights in the Constitution. Without life in the sense of existence, it would not be possible to exercise rights or to be the bearer of them. But the right to life was included in the Constitution not simply to enshrine the right to existence. It is not life as mere organic matter that the Constitution cherishes, but the right to human life: the right to share in the experience of humanity. This concept of human life is at the centre of our constitutional values. The Constitution seeks to establish a society where the individual value of each member of the community is recognised and treasured. The right to life is central to such a society. The right to life, thus understood, incorporates the right to dignity. So the rights to human dignity and life are entwined. The right to life is more than existence, it is a right to be treated

[243] S 11 Constitution of the Republic of South Africa, 1996.
[244] *S v Makwanyane* 1995 (3) SA 391 (CC) at 27; Currie I and De Waal J *The Bill of Rights Handbook* (2013) 259.
[245] *Christian Lawyers Association of South Africa v Minister of Health* 1998 (4) SA 1113 (T). The issue of living wills and pregnancy is discussed in more detail in Chapter 5 para 5.9.
[246] *S v Makwanyane* 1995 (3) SA 391 (CC).

as a human being with dignity: without dignity, human life is substantially diminished. Without life, there cannot be dignity".[247]

The right to life is therefore inextricably connected to the right to dignity. The right to dignity in life extends from the beginning of life to the end of life and therefore the rights to life and dignity are crucial in the realm of end-of-life decisions and living wills. Since the rights to life and dignity are "entwined"[248] the right to life incorporates more than mere physical existence, but an existence consonant with human dignity.[249] So too is the right to end life with dignity.[250]

In countries where euthanasia is legal, not only the right to life, but also the right to die is recognised, either through the legalisation of assisted suicide or legalisation of physician assisted suicide. Death is regarded to be a natural phenomenon flowing from life. The South African Constitutional Court in *Soobramoney*[251] case said that there is in reality no meaningful way in which the right to life can be constitutionally extended to encompass the right to evade death indefinitely.[252] The Constitutional Court further referred to the case of *Cruzan v Director Missouri Department of Health*[253] in which the American Supreme Court said that "dying is part of life, its completion rather than its opposite. We can, however, influence the manner in which we come to terms with our mortality".[254] Fabricius J in the *Stransham-Ford*[255] decision agreed with the applicant's contention that the right to die with dignity is regarded as a fundamental human right.[256]

[247] *S v Makwanyane* 1995 (3) SA 391 (CC) at 326 - 327.
[248] *S v Makwanyane* 1995 (3) SA 391 (CC) at 327.
[249] Currie I and De Waal J *The Bill of Rights Handbook* (2013) 267.
[250] See discussion on the right to dignity in para 2.3.3.
[251] *Soobramoney v Minister of Health, KwaZulu-Natal* 1998 1 SA 765 (CC).
[252] *Soobramoney v Minister of Health, KwaZulu-Natal* 1998 1 SA 765 (CC) at 57.
[253] *Cruzan v Director Missouri Department of Health* 497 US 261 (1990).
[254] *Cruzan v Director Missouri Department of Health* 497 US 261 (1990) at 343; *Soobramoney v Minister of Health, KwaZulu-Natal* 1998 1 SA 765 (CC) at 57.
[255] *Stransham-Ford v Minister of Justice and Correctional Services and Others* 2015 (4) SA 50 (GP).
[256] *Stransham-Ford v Minister of Justice and Correctional Services and Others* 2015 (4) SA 50 (GP) at 28.

However the High Court's decision was overturned by the subsequent Supreme Court of Appeal decision.[257]

According to Carstens "… there can be no doubt that the human body is, not only in life, but also in death, endowed with the ethical value of human dignity, even though no longer with life, bodily integrity or privacy."[258]

On the interpretation of the right to life, the Constitutional Court held in *Soobramoney*[259] that the right to life did not impose a positive obligation on the state to provide life-saving treatment to a critically ill patient. The Constitutional Court said that the positive obligations on the state to provide medical treatment were expressly stated in section 27 which is the right to health care. Therefore the right to life could not be interpreted to impose additional health care obligations on the state that would be inconsistent with section 27.[260] In the health care context the preservation of life is dependent on the availability of health care resources. The right to life can therefore be limited as was done in the *Soobramoney*[261] case where a limitation was placed on the state's duty to protect, promote and fulfil the right to life when there is a request for life to be prolonged indefinitely through the provision of state health care services.[262]

In *S v Makwanyane*[263] the court posed complex questions:

> "What does [[e]veryone has the right to life] mean? What is a "person"? When does "personhood" and "life" begin? Can there be a conflict between the "right to life" in section 9 and the right of a mother to "personal privacy" in terms of section

[257] *Minister of Justice and Correctional Services v Estate Late James Stransham-Ford* [2017] 1 All SA 354 (SCA). See Chapter 5 paras 5.10.5.3 & 5.10.5.4 for discussion on *Stransham-Ford* High Court and Supreme Court of Appeal decisions.
[258] Carstens P "Revisiting the infamous Pernkopf Anatomy Atlas: historical lessons for medical law and ethics" *Fundamina* (2012) 18 (2) 40.
[259] *Soobramoney v Minister of Health, KwaZulu-Natal 1998* 1 SA 765 (CC).
[260] *Soobramoney v Minister of Health, KwaZulu-Natal* 1998 1 SA 765 (CC).
[261] *Soobramoney v Minister of Health, KwaZulu-Natal* 1998 1 SA 765 (CC).
[262] S 11 read with S7(2) Constitution of the Republic of South Africa, 1996 read with S 27 Constitution of the Republic of South Africa, 1996 and *Soobramoney v Minister of Health, KwaZulu-Natal* 1998 1 SA 765 (CC).
[263] *S v Makwanyane* 1995 (3) SA 391 (CC).

13 and her possible right to the freedom and control of her body? Does the "right to life", within the meaning of section 9, preclude the practitioner of scientific medicine from withdrawing the modern mechanisms which mechanically and artificially enable physical breathing in a terminal patient to continue, long beyond the point, when the "brain is dead" and beyond the point when a human being ceases to be "human" although some unfocussed claim to qualify as a "being" is still retained? If not, can such a practitioner go beyond the point of passive withdrawal into the area of active intervention? When? Under what circumstances?"[264]

The court however did not venture answers to these difficult questions, but noted the complexity thus opening the debate and paving the way for further end-of-life and living will discussions and court applications.

According to Carstens and Pearmain the concept of life is in reality "not readily described or defined" and "its complexity" is "often highlighted by the many different emotionally charged situations that present in the context of health services delivery".[265]

However, the right to life also does not mean that a life has to be artificially preserved when a person is clinically dead.[266] Once a person is declared dead, life-sustaining equipment and treatments may be stopped.

A legal and mentally competent person may request the refusal of life-prolonging treatment contemporaneously, in other words through words and actions at the time when the decision to continue or initialise life-prolonging treatment has to be made. These instructions may be given in advance in the form of a living will. If a person is still mentally competent to convey the instructions him- or herself, the living will shall not be of any use or effect. The living will should only come into operation once the maker is deemed medically incompetent.

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[264] *S v Makwanyane* 1995 (3) SA 391 (CC) at para 268.
[265] Carstens P & Pearmain D *Foundational Principles of South African Medical Law* (2007) 28.
[266] *S v Williams* 1986 (4) SA 1188 (A).

The *Clarke v Hurst*[267] case dealt with the dilemma of the possible withdrawal of life-prolonging treatment from a mentally incompetent patient in the pre-Constitutional era. Dr Clarke (the patient) had suffered a heart attack which resulted in complete cessation of his breathing and heartbeat. However, his heartbeat was restored after resuscitation, but since he had been deprived of oxygen to the brain for a prolonged period, he had suffered serious and irreversible brain damage. As a result of this brain injury he remained in a comatose state, and in addition he was unable to swallow and had to receive feeding through a naso-gastric tube. Dr Clarke did have a living will which was unfortunately discovered only after he had been subjected to life-sustaining measures. This situation continued for four years after which he still remained in a persistent vegetative state. At this point in time Mrs Clarke applied to the court to be appointed as *curatrix personae* of her husband. She wished to obtain the power to authorise the discontinuation of any further medical treatment including artificial feeding. She requested a court order declaring to the effect that she would not be acting unlawfully if she were to withhold permission to medical treatment or if she were to authorise that artificial life-sustaining measures be discontinued, even if such discontinuance would end her husband's life.

The court did not venture an opinion on the legal validity of the living will, but did however take note of Dr Clark's living will and the fact that he had previously spoken out in favour of passive euthanasia. The court subsequently stated that:

> "It is indeed difficult to appreciate a situation, save where the patient is suffering unbearable pain or is in a vegetative state, where it would be in his best interests not to exist at all. The patient in the present case has, however, passed beyond the point where he could be said to have an interest in the matter. But just as a living person has an interest in the disposal of his body, so I think the patient's wishes as expressed when he was in good health should be given effect."[268]

The court distinguished between "human life" and "biological life", and found that:

[267] *Clarke v Hurst NO and others* 1992 4 SA 630 (D).
[268] *Clarke v Hurst NO and others* 1992 4 SA 630 (D) at par 17.

> "life in the form of certain biological functions such as heartbeat, respiration, digestion and blood circulation but unaccompanied by any cortical and cerebral functioning of the brain, cannot be equated with living in the human or animal context".[269]

The court held that because the capacity of Dr Clarke's brain for cognitive and collative life had been destroyed and the destruction of this capacity was irreparable, "the brain has permanently lost the capacity to induce a physical and mental existence at a level which qualifies as human life".[270] This meant that "judged by society's legal convictions, the feeding of the patient does not serve the purpose of supporting human life as it is commonly known" and the applicant, if appointed as *curatrix,* would act reasonably and would be justified in discontinuing the artificial feeding and would therefore not be acting wrongfully if she were to do so".[271] The court therefore found that passive euthanasia was legal. This judgment was criticised on the point that the court did not recognise the patient's right to autonomy.[272] According to van Oosten, patient autonomy entails that the patient is viewed as master of his own body and health and therefore has the right to take own decisions to undergo or refuse medical treatment.[273] This criticism highlights the moral and ethical dilemma of the law in taking decisions on matters regarding the prolonging of human life when the quality of such life is questionable.[274] It is important to remember that the *Clarke v Hurst* decision was decided in 1992 before the Constitutional dispensation. Therefore, the court did not make mention of any fundamental rights contained in the Constitution. If the case were to be decided today, the court would most definitely look at the right to dignity when discussing quality of life.

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[269] *Clarke v Hurst* 1992 (4) SA 630 D at par 17.
[270] *Clarke v Hurst NO and others* 1992 4 SA 630 (D) at 649.
[271] *Clarke v Hurst NO and others* 1992 4 SA 630 (D) at 649.
[272] Slabbert M & van der Westhuizen C "Death with dignity in lieu of euthanasia" (2007) 22 *SAPR/PL* 368.
[273] Van Oosten FFW *The doctrine of informed consent in Medical Law* LLD Dissertation (1989) 13.
[274] See discussion on quality of life and dignity in par 2.3.3.

The comparative provision for the right of life as enshrined in section 11 of the South African Bill of Rights, is section 7 of the Canadian Charter of Rights and Freedoms. Section 7 reads as follows:

> "Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice." [275]

In the *Carter v Canada*[276] case, the Supreme Court of Canada had to determine whether the criminal prohibition on assisted suicide violated the rights contained in section 7 of the *Charter* namely the rights to life, liberty and security of the person[277] of competent adults who suffer intolerably as a result of a grievous and irremediable medical condition, and to equal treatment by and under the law.[278] The court was thus requested to balance on the one hand the autonomy and dignity of a competent adult who seeks death in response to a grievous and irremediable medical condition, and on the other hand the sanctity of life and the need to protect the vulnerable.

The Supreme Court found that sections 241(*b*) and 14 of the Criminal Code unjustifiably infringe section 7 of the Charter and are of no force or effect to the extent that they prohibit physician assisted death for a competent adult person who firstly clearly consents to the termination of life and secondly has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition. The court found that properly designed and administered safeguards exist which could protect vulnerable people from abuse and error. The court concluded that individuals who meet rigorous criteria should be able to avail themselves of assistance in dying.[279]

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[275] S 7 Canadian Charter of Rights and Freedoms, Constitution Act 1982.
[276] *Carter v Canada* 2015 SCC 5.
[277] S 7 Canadian Charter of Rights and Freedoms.
[278] S 15 Canadian Charter of Rights and Freedoms.
[279] See full discussion on the *Carter v Canada* 2015 SCC 5 case in Chapter 4 par 4.5. Cf discussion of *Carter v Canada* 2015 SCC 5 in Palmer S "'The choice is cruel': assisted suicide and Charter rights in Canada" (July 2015) 74 02 *The Cambridge Law Journal* 191-194.

2.3.3 The Right to Dignity

In the South African law the right to dignity is regarded as an independent personality interest. Section 10 of the South African Constitution enshrines the fundamental constitutional right to dignity:

> "Everyone has inherent dignity and the right to have their dignity respected and protected."[280]

According to Section 1 of the Constitution, the Republic of South Africa is founded on the values of "human dignity, the achievement of equality and the advancement of human rights and freedoms".[281] The importance of human dignity is thus emphasised. According to Devenish:

> "Human dignity encapsulates those characteristics of persons that distinguish them from other creatures and inanimate things. The gravamen of the right to human dignity is that persons must be treated in a manner befitting human beings and not in a subhuman manner."[282]

In the *S v Makwanyane*[283] case it was said that "recognition and protection of human dignity is the touchstone of the new political order and is fundamental to the new constitution."[284] According to O'Regan J in *S v Makwanyane*:

> "The importance of dignity as a founding value of the new Constitution cannot be overemphasised. Recognising a right to dignity is an acknowledgement of the intrinsic worth of human beings: human beings are entitled to be treated as worthy of respect and concern. This right therefore is the foundation of many of the other rights that are specifically entrenched in chapter 3."[285]

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[280] S10 Constitution of the Republic of South Africa, 1996.
[281] S1 Constitution of the Republic of South Africa, 1996.
[282] Devenish GE *The South African Constitution* (2005) 61.
[283] *S v Makwanyane* 1995 (3) SA 391 (CC).
[284] *S v Makwanyane* 1995 (3) SA 391 (CC) at 329.
[285] *S v Makwanyane* 1995 (3) SA 391 (CC) at 328.

After the human rights atrocities that took place during the era of Apartheid, the right to dignity, which connotes the intrinsic worth of human beings, precludes people from being treated as dehumanised or sub-human, in other words treating people in a manner that is not in line with the worth of being human, is prohibited.

In the *Dawood*[286] case, O'Regan J observed that:

> "The value of dignity in our Constitutional framework cannot therefore be doubted. The Constitution asserts dignity to contradict our past in which human dignity for black South Africans was routinely and cruelly denied. It asserts it too to inform the future, to invest in our democracy respect for the intrinsic worth of all human beings. Human dignity therefore informs constitutional adjudication and interpretation at a range of levels. It is a value that informs the interpretation of many, possibly all, other rights. This Court has already acknowledged the importance of the constitutional value of dignity in interpreting rights such as the right to equality, the right not to be punished in a cruel, inhuman or degrading way, and the right to life. Human dignity is also a constitutional value that is of central significance in the limitations analysis. Section 10, however, makes it plain that dignity is not only a value fundamental to our Constitution, it is a justiciable and enforceable right that must be respected and protected. In many cases, however, where the value of human dignity is offended, the primary constitutional breach occasioned may be of a more specific right such as the right to bodily integrity, the right to equality or the right not to be subjected to slavery, servitude or forced labour."[287]

Mokgoro J remarked in the *S v Makwanyane* case that life and dignity are two sides of the same coin; therefore a violation to the right of life would be a violation to the right to dignity.[288]

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[286] *Dawood v Minister of Home Affairs*; *Shalabi v Minister of Home Affairs*; *Thomas v Minister of Home Affairs* 2000 (3) SA 936 (CC).
[287] *Dawood v Minister of Home Affairs*; *Shalabi v Minister of Home Affairs*; *Thomas v Minister of Home Affairs* 2000 (3) SA 936 (CC) at 35.
[288] *S v Makwanyane* 1995 (3) SA 391 (CC) at 220.

In the *National Coalition for Gay and Lesbian Equality*[289] case the Constitutional Court said that dignity is a "a difficult concept to capture in precise terms" but "requires us to acknowledge the value and worth of all individuals as members of society".[290]

Since earliest times the idea of a "common morality" being essential for people to live together in communities has been a concept that has received attention from philosophers, theologians and jurists. Hugo de Groot (Grotius) was of the view that the fundamental principles of law and morality, and therefore human worth, would be binding notwithstanding individual belief systems.[291] Dworkin states that people have a right not to suffer indignity as he explains it: the right "not to be treated in ways that in their culture or community are understood as showing disrespect".[292] According to Neethling, Potgieter and Visser dignity "embraces a person's subjective feelings of dignity or self-respect".[293]

Woolman and Bishop refer to the five meanings of dignity.[294] The first explanation is that an individual is an end in him– or herself. The history of this meaning of dignity can be traced back to the philosopher Immanuel Kant's moral philosophy which states that human dignity gives humans intrinsic worth.[295] The second meaning is that dignity encompasses equal concern and respect. In *Christian Education South Africa v Minister of Education*[296] Sachs, J found that the right to equality does not mean that everyone is treated the same way, but that everyone is treated with "equal concern and respect". The third meaning of dignity is that of self-actualisation, as Ackermann, J stated in the *Ferreira v Levin*[297] case:

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[289] *National Coalition for Gay and Lesbian Equality v Minister of Home Affairs* 2000 (2) SA 1 (CC).
[290] *National Coalition for Gay and Lesbian Equality v Minister of Home Affairs* 2000 (2) SA 1 (CC) at 29.
[291] Ackermann L *Human Dignity: Lodestar for Equality in South Africa* (2012) 30.
[292] Dworkin R *Life's Dominion* (1993) 233.
[293] Neethling J, Potgieter JM & Visser PJ *Neethling's law of personality* (2005) 192.
[294] Woolman S, Roux T and Bishop M *Constitutional Law of South Africa* (2007) 36-7 – 36-17.
[295] Currie I and De Waal J *The Bill of Rights Handbook* (2013) 251.
[296] *Christian Education South Africa v Minister of Education* 2000 (10) BCLR 1051 (CC) at 42.
[297] *Ferreira v Levin* 1996 (1) SA 984 (CC).

> "Human dignity cannot be fully valued or respected unless individuals are able to develop their humanity, their 'humanness' to the full extent of its potential. Each human being is uniquely talented. Part of the dignity of every human being is the fact and awareness of this uniqueness. An individual's capacity cannot be fully respected or valued unless the individual is permitted to develop his or her unique talents optimally. Human dignity has little value without freedom; for without freedom personal development and fulfilment are not possible. Without freedom, human dignity is little more than an abstraction. Freedom and dignity are inseparably linked. To deny people their freedom is to deny them their dignity."[298]

The fourth meaning that Woolman and Bishop attach to dignity is that of self-governance. The authors describe this capacity for self-governance as "the capacity of (almost) all human beings to reason their way to the ends that give their lives meaning … [which makes] democracy the only acceptable secular form of political organization".[299] The fifth meaning of dignity is "the collective responsibility for the material conditions of agency" in terms of which dignity does not just attach to the individual, but binds the members of community together, where there is mutual recognition.[300] This notion of "community" is evident in the African tradition of *Ubuntu*. In terms of the culture of *Ubuntu* emphasis is placed on communality and interdependence of the members of the community. In the *Makwanyane*[301] case the concept of *Ubuntu* was described as follows:

> "It is a culture which places some emphasis on communality and on the interdependence of the members of a community. It recognises a person's status as a human being, entitled to unconditional respect, dignity, value and acceptance from the members of the community such person happens to be part of. It also entails the converse, however. The person has a corresponding duty to

[298] *Ferreira v Levin* 1996 (1) SA 984 (CC) at 49.
[299] Woolman S, Roux T and Bishop M *Constitutional Law of South Africa* (2007) 36-12 – 36-13.
[300] Woolman S, Roux T and Bishop M *Constitutional Law of South Africa* (2007) 36-15.
[301] *S v Makwanyane* 1995 (3) SA 391 (CC).

give the same respect, dignity, value and acceptance to each member of that community. More importantly, it regulates the exercise of rights by the emphasis it lays on sharing and co-responsibility and the mutual enjoyment of rights by all."[302]

"Human dignity" therefore has a wide ambit which encompasses different aspects and values such as life, privacy and freedom.[303] Therefore the right to dignity is also not easily separated from the right to life, privacy and freedom and security of a person, as dignity is inherent to all these rights. The court in *Stransham-Ford*[304] case said that:

> "there is a very close link between human dignity and privacy and as well as a close relationship with freedom, and Applicant correctly relied on the inter-relationship between these concepts."[305]

Foster states that dignity is "the bioethical Theory of Everything" which can unlock all problems in medical ethics and bioethics, especially "the outlandish frontiers of bioethics".[306] Foster explains that "…it is possible to give dignity a meaning that makes it effective at the bioethical and medico-legal coalface, and that that meaning can be empirically derived from a broadly anthropological look at what makes human beings thrive".[307]

The right to dignity is thus of fundamental importance in the context of end-of-life decisions and living wills. Chaskalson confirmed the fundamental importance of the rights to life and dignity in the *Makwanyane*[308] case:

> "The rights to life and dignity are the most important of all human rights, and the source of all other personal rights in Chapter Three. By committing ourselves to a

[302] *S v Makwanyane* 1995 (3) SA 391 (CC) at 224.
[303] *S v Makwanyane* 1995 (3) SA 391 (CC) 327; *Stransham-Ford v Minister of Justice and Correctional Services and Others* 2015 (4) SA 50 (GP).
[304] *Stransham-Ford v Minister of Justice and Correctional Services and Others* 2015 (4) SA 50 (GP).
[305] *Stransham-Ford v Minister of Justice and Correctional Services and Others* 2015 (4) SA 50 (GP) at 12.
[306] Foster C *Human Dignity in Bioethics and Law* (2011) 1-4.
[307] Foster C *Human Dignity in Bioethics and Law* (2011) 3.
[308] *S v Makwanyane* 1995 (3) SA 391 (CC).

society founded on the recognition of human rights we are required to value these two rights above all others."[309]

In the context of medical law and health care, dignity is often equated to quality of life.[310] The right to dignity is more fundamental than the right to *beneficence*.[311] A person who no longer enjoys quality of life is said to have diminished dignity. The court in the *Stransham-Ford* case stated that the "sacredness of the quality of life should be accentuated rather than the sacredness of life *per se*".[312] According to Jordaan: "One of the paramount concerns of patients who wish to end their own, personal suffering is to preserve their dignity".[313] Ackermann argues that certain aspects of human dignity pre-date birth and survive death, but that it is the Constitution that must determine when the various aspects of the right to dignity as contained in the Constitution, begin and cease.[314]

The importance of the right to dignity in end-of-life decisions is illustrated by the emphasis on the concept of dignity in the names of societies worldwide which aid individuals with end-of-life decisions such as Dignity SA (South Africa), Dying with Dignity (Canada), Dignity in Dying (England) and Dignitas (Switzerland).

2.3.4 The Right to Privacy

The right to privacy is related to the right to dignity. Privacy has been recognised as an independent personality right by the common law.[315] Privacy is in fact a component of

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[309] *S v Makwanyane* 1995 (3) SA 391 (CC) at 144.
[310] Carstens P and Pearmain D *Foundational Principles of the South African Medical Law* (2007) 29.
[311] Dworkin R "Life past reason" in *Life's Dominion* (1993) 233.
[312] *Stransham-Ford v Minister of Justice and Correctional Services and Others* 2015 (4) SA 50 (GP) at 28.
[313] Jordaan L "The right to die with dignity: a consideration of the constitutional arguments" (2009) *THRHR* 201.
[314] Ackermann L *Human Dignity: Lodestar for Equality in South Africa* (2012) 52.
[315] *O'Keeffe v Argus Printing and Publishing Co Ltd* 1954 3 SA 244 (C); *National Media Ltd v Jooste* 1996 3 SA 262 (A) 271; *Jooste v National Media Ltd* 1994 2 SA 634 (C) 645; *Universiteit van Pretoria v Tommie Meyer Films (Edms) Bpk* 1977 4 SA 376 (T) 384; *Bernstein v Bester* 1996 2 SA 751 (CC) 789. See Neethling J, Potgieter JM & Visser PJ *Neethling's law of personality* (2005) 217.

the concept of "dignitas".[316] According to Neethling, Potgieter and Visser "the lack of a sufficient degree of privacy may negatively influence a person's whole physical-mental makeup".[317] Since the Constitutional dispensation, privacy has been regarded as a fundamental human right entrenched in Section 14 of the Constitution.[318] Section 14 of the Constitution determines that:

"Everyone has the right to privacy, which includes the right not to have

a. their person or home searched;

b. their property searched;

c. their possessions seized; or

d. the privacy of their communications infringed."[319]

The right to privacy consists of two parts. The first part contains a general right to privacy and the second part lists the specific infringements of privacy that are protected.[320] In the *Jansen van Vuuren NNO v Kruger*[321] decision the Appellate Division held that health care providers have an ethical and a legal duty to respect patients' confidentiality, originating from our common law. The court found that when health care providers breach their duty of confidentiality in terms of the doctor-patient relationship, patients would have a legal remedy.

In the *Bernstein v Bester*[322] case the Constitutional Court held that:

> "the concept of privacy is an amorphous and elusive one which has been the subject of much scholarly debate. The scope of privacy has been closely related to the concept of identity and it has been stated that 'rights, like the right to

[316] Currie I and De Waal J *The Bill of Rights Handbook* (2013) 296.
[317] Neethling J, Potgieter JM & Visser PJ *Neethling's Law of Personality* (2005) 29.
[318] Constitution of the Republic of South Africa, 1996.
[319] S 14 Constitution of the Republic of South Africa, 1996.
[320] Devenish GE *The South African Constitution* (2005) 79.
[321] *Jansen van Vuuren NNO v Kruger* 1993 (4) SA 842 (A).
[322] *Bernstein v Bester* 1996 (2) SA 751 (CC).

privacy, are not based on a notion of the unencumbered self, but on the notion of what is necessary to have one's own autonomous identity'".[323]

The right to privacy is thus an independent personality right and part of the concept of human dignity and human worth. O'Regan, J in the *Khumalo v Holomisa*[324] Constitutional Court decision stated that:

> "It should be noted that there is a close link between human dignity and privacy in our constitutional order. The right to privacy, entrenched in s14 of the Constitution, recognises that human beings have a right to a sphere of intimacy and autonomy which should be protected from invasion. This right serves to foster human dignity. No sharp lines then can be drawn between reputation, *dignitas* and privacy in giving effect to the value of human dignity in our Constitution."

Neethling, Potgieter and Visser state that this view of O'Regan, J can be accepted with a *proviso* that there must not be a "complete blurring of the distinction between privacy and dignity, thereby creating legal uncertainty".[325]

The right to privacy entails the individual's freedom to make personal choices freely and to determine for him- or herself which facts about his or her person must be kept private, and not form part of the knowledge of others.[326] The right to privacy entails making personal choices without state interference and it should include life and death choices. Human beings possess bodily privacy and decisions taken in that regard (such as medical decisions taken contemporaneously or by means of an advance directive or living will) should fall under the right to privacy. Furthermore, personal communications and information (such as the contents of a living will) may also fall under the right to privacy. Jordaan agrees that the right to privacy should be applicable to a decision to

[323] Per Ackermann J in *Bernstein v Bester* at 65 quoting R Frost "How not to speak about identity: the concept of the person in a theory of justice" (1992) *Philosophy and Social Criticism* 18 1 para 65.
[324] *Khumalo v Holomisa* 2002 5 SA 401 (CC) 419.
[325] Neethling J, Potgieter JM & Visser PJ *Neethling's law of personality* (2005) 219 fn 28.
[326] Neethling J, Potgieter JM & Visser PJ *Neethling's Law of Personality* (2005) 30-31.

refuse medical treatment, which could be conveyed by means of an advance directive.[327] Jordaan further states that the right to privacy should naturally extend to an individual's choice to end his or her own life and could involve seeking physician assisted suicide.[328]

However in the *Stransham-Ford* decision, the SCA referred to the *Pretty*[329] decisions. In the House of Lords *Pretty* decision the court found that the right to private life was relevant to the way in which people live their lives, which includes the manner in which a dying person is treated. However, the right to private life was found to be unrelated to the manner in which a person might wish to die and did not confer a right to end a human's life by assisted suicide. The European Court of Human Rights in the *Pretty* Appeal decision stated that the right to decide by what means and at what point life will end, is an aspect of the right to private life.[330]

2.3.5 The Right to Equality

Equality is a recurrent theme in the Constitution which indicates its significant importance with reference to South Africa's history of inequality. According to Devenish equality is "symbolically the most important right in the Constitution".[331] In *Brink v Kitshoff NO* the Constitutional Court referred specifically to the historical interpretation of the equality clause. The court held that Section 8 of the Interim Constitution:

> "is the product of our own particular history. Perhaps more than any of the other provisions in chapter 3, its interpretation must be based on the specific language of section 8, as well as our own constitutional context. Our history in South Africa is of particular relevance to the concept of equality. The policy of apartheid, in

[327] Jordaan L "The legal validity of an advance refusal of medical treatment in South African law (part 1)" *De Jure* (2011) 43.
[328] Jordaan L "The right to die with dignity: a consideration of the constitutional arguments" (2009) *THRHR* 201. Jordaan L "The legal validity of an advance refusal of medical treatment in South African law (part 1)" *De Jure* (2011) 43.
[329] *Pretty v Director of Public Prosecutions and Secretary of State for the Home Department* [2001] UKHL 61; [2002] 1 All ER (HL); *Pretty v United Kingdom* [2002] 35 EHRR.
[330] See discussion of the *Pretty* decisions in Chapter 4 para 4.4.5.2.2.1.
[331] Devenish GE *The South African Constitution* (2005) 47.

law and in fact, systematically discriminated against black people in all aspects of social life. Black people were prevented from becoming owners of property or even residing in areas classified as 'white', which constituted nearly ninety percent of the landmass of South Africa; senior jobs and access to schools and universities were denied to them; civic amenities, including transport systems, public parks, libraries and many shops were also closed to black people. Instead, separate and inferior facilities were provided. The deep scars of this appalling programme are still visible in our society. It is in the light of that history and the enduring legacy that it bequeathed that the equality clause needs to be interpreted".[332]

It is difficult to separate the concepts of dignity and equality. The preamble to the Constitution states that:

> "...there is a need to create a new order in which all South Africans will be entitled to a common South African citizenship in a sovereign and democratic constitutional state in which there is equality between men and women and people of all races…"[333]

Section 33(1) of the Constitution states that rights entrenched in the Bill of Rights may only be limited to the extent that it is "justifiable in an open and democratic society based on freedom and equality".[334]

Section 9 of the South African Constitution determines that:

> "1. Everyone is equal before the law and has the right to equal protection and benefit of the law.
>
> 2. Equality includes the full and equal enjoyment of all rights and freedoms. To promote the achievement of equality, legislative and other measures designed to

[332] *Brink v Kitshoff NO* 1996 (4) SA 197 (CC) at para 40.
[333] Preamble Constitution of South Africa, 1996.
[334] S 33(1) Constitution of the Republic of South Africa, 1996

protect or advance persons, or categories of persons, disadvantaged by unfair discrimination may be taken.

3. The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth.

4. No person may unfairly discriminate directly or indirectly against anyone on one or more grounds in terms of subsection (3). National legislation must be enacted to prevent or prohibit unfair discrimination.

5. Discrimination on one or more of the grounds listed in subsection (3) is unfair unless it is established that the discrimination is fair."

The test for when the equality clause may be invoked was set out in *Harksen v Lane*[335]. This comprises a three step factual enquiry. There must firstly be a factual inquiry into whether there is differentiation between people or categories of people. Secondly, if such a differentiation is found to exist, it must be determined whether there is a rational connection to a legitimate government purpose. The court however said that even if there is a rational connection to a legitimate government purpose, it may still amount to discrimination. Therefore, it should be determined whether the differentiation amounts to unfair discrimination. If the discrimination is on a listed ground namely race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth, the court will presume unfairness until the contrary is proved. If the discrimination is on an unlisted ground the court will primarily focus on the impact of the discrimination on the complainant and complainants in the same position. Lastly, should the discrimination be found to be unfair, the court will have to determine whether the unfair discrimination can be justified under the Section 36 limitation clause.

[335] *Harksen v Lane and Others* 1998 (1) SA 300 (CC) at 53.

According to Currie and De Waal the right to equality as entrenched in section 9 does not prevent the government from making classifications or from treating some categories of people differently to others.[336] Firstly the differentiation in the law or conduct must have a legitimate purpose, and secondly there should be a rational connection between the differentiation and the purpose, otherwise the differentiation will violate section 9(1).[337]

The rights to dignity and equality are also closely linked. In terms of the Constitutional Court's decision in *Christian Education South Africa v Minister of Education,*[338] equality does however not mean that everyone is treated the same way, but that everyone is treated with equal concern and respect.[339] Dignity is impaired when a person is subjected to degrading or humiliating treatment or to conduct which treats a person as subhuman.

The comparable provision in the Canadian law is section 15 of the Canadian Constitution which states that:

> "Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability."[340]

In the *Carter v Canada*[341] case the Supreme Court of Canada said that it was not necessary to discuss whether section 15 of the Canadian Constitution had been violated by the prohibition on assisted suicide, because the Court had already found that section 7 (the right to life, liberty and security of the person) had been violated and that was sufficient for the application to succeed. However, in the Supreme Court of

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[336] Currie I and De Waal J *The Bill of Rights Handbook* (2013) 218.
[337] *Prinsloo v van der Linde* 1997 (3) SA 1012 (CC) 35. Currie I and De Waal J *The Bill of Rights Handbook* (2013) 219.
[338] *Christian Education South Africa v Minister of Education* 2000 (10) BCLR 1051 (CC).
[339] *Christian Education South Africa v Minister of Education* 2000 (10) BCLR 1051 (CC) at 42.
[340] S 15 Canadian Charter of Rights and Freedoms, Constitution Act 1982.
[341] *Carter v Canada* 2015 SCC 5 at 93.

British Columbia's *Carter*[342] decision, Lynn Smith, J held that the equality rights of one of the applicants, Mrs Taylor, had indeed been infringed by the absence of the option of physician assisted euthanasia. Mrs Taylor was unable to commit suicide due to the nature of her illness, and she would have been free to commit suicide if she had been able to do so, without the assistance of a medical practitioner. Lynn Smith, J held that Mrs Taylor's equality rights had been breached because other people who are in a similar situation, but who are not disabled, could do so. In the *Stransham-Ford* decision the Supreme Court of Appeal said that "it is debatable whether this ground of distinction (on equality rights) can find place within the framework of the provisions of s 9(3) of the Constitution".[343]

2.3.6 The Right to Freedom and Security of the Person which includes the Right to Bodily and Psychological Integrity

The right to freedom and security of the person which includes the right to bodily and psychological integrity is also very important in the field of living wills and end-of-life decisions. According to Currie and De Waal the right to freedom and security of the person is in essence the right to be left alone.[344]

Section 12(2) of the South African Constitution guarantees the right to bodily and psychological integrity, which forms part of the right to freedom and "security in" and "control over" one's body, and therefore also guarantees the right to refuse medical treatment (the right to patient autonomy).[345]

Section 12(2)(b) therefore comprises two elements: "security in" and "control over your body". "Security in" means the protection of bodily integrity without any intrusion from the state or someone else. "Control over" means the protection of bodily autonomy or

[342] *Carter v. Canada* (Attorney General) 2012 BCSC 886.
[343] My addition. *Minister of Justice and Correctional Services v Estate Late James Stransham-Ford* [2017] 1 All SA 354 (SCA) at 66.
[344] Currie I & De Waal J *The Bill of Rights Handbook* (2013) 287.
[345] S 12(2) Constitution of the Republic of South Africa, 1996.

self-determination against interferences. Currie and De Waal explain that “security in” is “the right to be left alone in the sense of not being molested by others” and “control over” means “the right to be left alone in the sense of being allowed to live the life one chooses” and by analogy to choose the manner and time of one’s death.[346]

A patient with full mental and legal capacity has the right to request or refuse medical treatment under the South African law.[347] It is however a prerequisite for the request or refusal of medical treatment that the patient must have given informed consent. The patient must therefore have been fully informed of the consequences of treatment options or refusal thereof; furthermore the patient must have understood the nature of the consequences and must have given the instructions for the medical procedure, for example instructions that life-prolonging treatment be discontinued.

The doctrine of informed consent is rooted in consent as a defence to not incur criminal or civil liability.[348] The common law legal principle is *volenti non fit injuria* (an injury is not done to one who consents). Should a person who is capable of expressing his own free will, provide legally valid consent to any possible physical or mental injury, the harm which resulted, would be regarded as lawful.[349] For example, where a patient consented to run the risk of serious harm or even death, will excuse physical injury inflicted by medical personnel in the course of normal therapeutic medical operations or treatments.[350]

According to Van Oosten technological and organisational developments in the medical field have led to a depersonalisation of the doctor-patient relationship.[351] The onset of the Constitutional dispensation introduced a new era as patients’ rights have since been protected in the Bill of Rights. The doctor-patient relationship has furthermore

[346] Currie I and De Waal J *The Bill of Rights Handbook* (2013) 287.
[347] See Chapter 1 para 1.1.3 for a discussion on incapacity.
[348] See discussion on the requirements for informed consent in Chapter 3 para 3.4.
[349] Neethling J, Potgieter JM & Visser PJ *Neethling’s law of personality* (2005) 98.
[350] Burchell J *Principles of Criminal Law* (2016) 326.
[351] Van Oosten FFW *The doctrine of informed consent* (1989) LLD Dissertation 12.

undergone a psychological change. Doctors are no longer viewed with old-world mysticism, but rather as professionalised and consumer-orientated service providers with doctors and patients being equal partners.[352] The ultimate decision to undergo (informed consent to) or refuse (informed refusal of) medical procedures or interventions lies with the patient and not primarily with the doctor. Accordingly, patient autonomy as a fundamental right has been endorsed and medical paternalism rejected.

Personal autonomy is said to comprise different components, namely the autonomy of thought, the autonomy of will and the autonomy to act accordingly.[353] Together these components support the notion that human beings can think for themselves, make decisions and act accordingly.[354] The strict legal enforcement of living wills promotes patient autonomy (individual choice) and rejects the idea of medical paternalism.

Medical interventions without the patient's consent on the basis of the "best interest of the patient" could in certain circumstances constitute a violation of the patient's autonomy, for example where the patient was in a position to have consented or refused, but was not asked due to specific circumstances for example the urgent nature of the intervention.

Even if, from the point of view of the medical professional, a refusal by the patient to undergo the proposed intervention would be grossly unreasonable and might result in his or her death, and even if the medical profession takes the view that the disclosure of the risks and dangers in such circumstances may be unnecessary or undesirable, such actions could still amount to a violation of the patient's autonomy. Therefore, in the absence of other grounds of justification, medical interventions without the patient's informed consent (explicit or in writing), but based on "patient's-best-interest" and the "doctor-knows-best" criteria could constitute a violation of the patient's autonomy.

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[352] Van Oosten FFW *The doctrine of informed consent* (1989) LLD Dissertation 12-13.
[353] Gillion R "Philosophical Medical Ethics" (1985) in H Biggs *Euthanasia Death with Dignity and the Law* (2001) 95.
[354] Gillion R "Philosophical Medical Ethics" (1985) in H Biggs *Euthanasia Death with Dignity and the Law* (2001) 95.

In terms of the Law Commission of South Africa's Discussion Paper on Euthanasia and the Artificial Preservation of Life,[355] South African courts would acknowledge the medical practitioner's obligation to comply with a patient's request for cessation of life-prolonging treatment if there was informed consent. In complying with the request, the medical practitioner would not be acting unlawfully, either according to criminal law or in terms of private law, even if such an action would have the effect of hastening death.[356] The validity of the living will has thus far not been judicially examined. In the *Clarke v Hurst*[357] and *Stransham-Ford*[358] cases, the respective courts did not pronounce on the legal status of living wills, but did refer to a patient's right to refuse medical treatment.[359] The South African Law Commission has pronounced a living will should be recognised insofar as it requests a passive form of cessation of life.[360]

In the *Carter* decision the court found that physician assisted suicide is:

> "rooted in [a person's] control over their bodily integrity; it represents their deeply personal response to serious pain and suffering. By denying them the opportunity to make that choice, the prohibition impinges on their liberty and security of the person".[361]

The SCA in the *Stransham-Ford* decision interpreted this finding of the court in *Carter* to mean that the right to liberty and security of the person, can be extended to include a right to determine the manner and timing of death.[362]

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[355] South African Law Commission *Euthanasia and the artificial preservation of life Project 86 Report* (1997) 17.
[356] See discussion on the doctrine of double effect in Chapter 3 para 3.4 Chapter 5 para 5.10.
[357] *Clarke v Hurst NO and others* 1992 4 SA 630 (D).
[358] *Minister of Justice and Correctional Services and Others v Estate Late James Stransham-Ford and Others* [2017] 1 All SA 354 (SCA).
[359] See *Clarke v Hurst* case discussions in Chapter 3 para 3.6.1 and *Minister of Justice and Correctional Services and Others v Estate Late James Stransham-Ford and Others* Chapter 5 para 5.10.
[360] Ss 6-8 Draft Bill on End of Life Decisions as contained in the South African Law Commission Report *Project 86 Euthanasia and the artificial preservation of life* (November 1998). See Chapter 3 para 5.3.3 for a further discussion on the validity of living wills in South Africa.
[361] *Carter v Canada* 2015 SCC 5 at 68.
[362] *Minister of Justice and Correctional Services v Estate Late James Stransham-Ford* [2017] 1 All SA 354 (SCA) at 64.

2.3.7 The Right to Freedom of Religion, Belief and Opinion

The right to freedom of religion, belief and opinion has its origins in the complex relationship between the state and church. Section 15 does not prevent the state from recognising or supporting a specific religion. However section 15 does require the state to treat all religions equally.[363]

Section 15 states that:

> "1. Everyone has the right to freedom of conscience, religion, thought, belief and opinion.
> 2. Religious observances may be conducted at state or state-aided institutions provided that –
> a. those observances follow rules made by the appropriate public authorities;
> b. they are conducted on an equitable basis
> c. attendance at them is free and voluntary.
> 3.a. This section does not prevent legislation recognising
>
> i) marriages concluded under any tradition, or a system of religious, personal or family law, or
>
> ii) systems of personal and family law under any tradition or adhered to by persons professing a particular religion.
>
> b. Recognition in terms of paragraph 3a must be consistent with this section and the other provisions of the Constitution."

In the *Phillips v De Klerk*[364] case, (which was decided before the advent of the Constitutional era) the Transvaal Provincial Division recognised that a patient of the Jehovah's Witness faith had a right to self-determination and thus a right to refuse medical treatment. The patient, being a Jehovah's Witness, refused medical treatment in the form of a life-saving blood transfusion on religious grounds. The court, by

[363] Currie I & De Waal J *The Bill of Rights handbook* (2013) 315.
[364] *Phillips v De Klerk* 1983 TPD (unreported) as described in SA Strauss *Doctor Patient and the Law* (2001) 29-31.

recognising the patient's right to refuse medical treatment, in essence accepted the patient's right to die. The court found that the mentally competent individual's right to control his own destiny in accordance with his own value system, his "selfbeskikkingsreg", must be rated even higher than his health and life; in the absence of an overriding social interest to the contrary.

In *Hay v B*[365] an infant's parents refused to consent to a blood transfusion for their infant on religious grounds. A paediatrician at the clinic where the child was treated, consequently applied to court for an urgent order, authorising her to administer a blood transfusion to the child. The paediatrician testified that although there could not be any guarantee that the child would survive if the blood transfusion was administered, in all probability the child would die if a blood transfusion was not administered.

The parents were opposed to the blood transfusion on two grounds. Firstly, that the acceptance of the blood was against their religious beliefs and secondly, they expressed concerns relating to the physical risk of infection associated with blood transfusions. The paediatrician (applicant) testified as to the procedures that are followed namely blood screening and the unlikelihood that blood that would be used for transfusion, would be contaminated.

The High Court overruled the parents' refusal to permit a blood transfusion for their child. The court said that in terms of s 28(2) of the Constitution, a "child's best interests are of paramount importance in every matter concerning the child". The court said that the child's best interests are thus the single most important factor to be considered when balancing competing rights and interests concerning children. The court stated that the duty to afford children protection fell on law enforcement agencies, all right-thinking people and ultimately the High Court, which is the upper guardian of all children in South Africa.[366]

[365] *Hay v B* 2003 (3) SA 492 (W).
[366] *Hay v B* 2003 (3) SA 492 (W) at 494I - 495A.

The court further held that the right to life was a value that was constitutionally protected and if the blood transfusion was not administered, the death of the infant would be imminent. The court said that the infant's right to life was inviolable and could be protected and it was in the best interests of the infant that this right should be protected.[367]

The court said that even though it is the upper guardian of all minors, proper consideration had to be given to the parents' reasons for refusal. The court held that while the parents' private religious beliefs had to be respected, on the evidence it was established that their beliefs negated the essential content of the infant's right to life. The paediatrician (applicant) was adamant that the infant's best chance of survival would be by the immediate administration of the blood transfusion. The court said while the parents' concerns were understandable, they were neither reasonable nor justifiable. Their private beliefs could not override the infant's right to life.[368]

The court further said that as the upper guardian of all minors it finds it in the best interests of the minor to receive the appropriate medical treatment, notwithstanding the refusal by the minor's parents to consent to it and therefore granted the order. The interests of the infant receiving the blood transfusion thus outweighed the reasons advanced by the parents.[369]

Even though adult Jehovah's Witnesses may refuse blood transfusions, where children are involved the Minister of Health can now in terms of the Children's Act[370] intervene and give consent for a child to be treated in cases where parents refuse unreasonably on behalf of the child or where the child himself refuses unreasonably to undergo a medical treatment or a surgical operation.[371]

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[367] *Hay v B* 2003 (3) SA 492 (W) at 495B/C - C/D.
[368] *Hay v B* 2003 (3) SA 492 (W) (At 495D - E.)
[369] *Hay v B* 2003 (3) SA 492 (W) (At 496A - A/B.)
[370] Children's Act 38 of 2005.
[371] Ss 129(7) & 129(8) Children's Act, 38 of 2005.

A competent patient should be able to convey his or her religion, belief, or opinion on future medical treatments in a detailed living will. However, the fact that a religion, belief or opinion was conveyed through a living will or direct oral communication, does not mean that it will be adhered to. In order for the State to fulfil its duty in terms of the right to be free from all forms of violence from either public or private sources (Section 12(1)(c) of the Constitution), the State may prohibit practices that cause physical or emotional harm to persons.[372] In the *Prince v President of the Law Society, Cape of Good Hope*[373] case, The Law Society of the Cape of Good Hope refused to register a Rastafarian applicant's contract of community service (articles) as it was not satisfied that the applicant was indeed a fit and proper person as required by the Attorney's Act.[374] The applicant had two prior convictions of the possession of dagga and intended to use the drug in future. The Constitutional Court found that the general statutory prohibition of possession of dagga (with the only exception being medical use of the drug) was a violation of the right to freedom of religion. The court said that Rastafarianism was indeed a religion wherein the use and consumption of dagga was of great importance. The statutory prohibition on the possession of dagga thus amounted to a limitation of the practical aspect of freedom of religion. The court was divided on the question of whether the limitation could be justified. The majority thought that an exception on religious grounds was not feasible as it would be difficult to police and it would undermine the general prohibition.

2.3.8 The Right to Health and Access to Health Care

According to Woolman and Bishop in international law, the right to health consists of the "right to health care" and the "right to health conditions".[375] The Constitution does not contain a direct reference to a right to health. However the right to access health care exists and health care and medical treatments are referred to in the various sections.[376]

[372] Currie I and De Waal J *The Bill of Rights Handbook* (2013) 323.
[373] *Prince v President of the Law Society, Cape of Good Hope* 2002 (2) SA 794 (CC).
[374] Attorney's Act, 53 of 1979.
[375] Woolman S, Roux T and Bishop M *Constitutional Law of South Africa* (Student Edition) (2007) 56A-5.
[376] S 27(1)(a) and s27(3) Constitution of the Republic of South Africa, 1996.

According to McQuoid-Mason and Dada "access to health care" entails that "people should have the opportunity to receive health-care services, and that such services should be available, usable and effective".[377] Carstens and Pearmain argue that the rights contained in the Bill of Rights are not "discrete legal concepts", but rather "elements of a system of fundamental rights that are inextricably interlinked".[378]

Thus it can be argued that there is a grouping of rights which, when viewed collectively, could be said to constitute a right to health. These rights are the right to life,[379] the right to dignity,[380] the right to bodily and psychological integrity,[381] the right to privacy,[382] the right to an environment that is not harmful to health or well-being;[383] the right to emergency medical treatment,[384] the right to access to healthcare services,[385] the rights to sufficient food and water and social security, including appropriate social assistance.[386] The World Health Organization's definition of "health" is: "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.[387]

Section 27 of the Constitution recognises the right to have access to health care, which includes emergency and end-of-life health care that could be described in a living will. The right to access to health care only guarantees *access* to health care and not actual medical care. Medical treatment is limited to the availability of state resources, but emergency medical treatment may not be refused.

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[377] McQuoid-Mason D & Dada M *A-Z of Nursing L*aw (2011) 3.
[378] Carstens P & Pearmain D *Foundational Principles of South African Medical Law* (2007) 25.
[379] S 11 Constitution of the Republic of South Africa, 1996.
[380] S 10 Constitution of the Republic of South Africa, 1996.
[381] S12(2) Constitution of the Republic of South Africa, 1996.
[382] S14 Constitution of the Republic of South Africa, 1996.
[383] S 24(a) Constitution of the Republic of South Africa, 1996.
[384] In terms of section 27(3) Constitution of the Republic of South Africa, 1996 "No one maybe refused emergency medical treatment". See discussion Chapter 5 para 5.5 on the applicability of living wills and advance directives in emergency situations.
[385] S 27(1) (a) Constitution of the Republic of South Africa, 1996.
[386] S 27(1)(b) Constitution of the Republic of South Africa, 1996.
[387] Preamble to the Constitution of the WHO as adopted by the International Health Conference, New York, 19-22 June 1946 by the representatives of 61 states (Official Records of the World Health Organisation no 2, 100) and entered into force on 7 April 1948.

Section 27 reads as follows:

"1. Everyone has the right to have access to-

a. health care services, including reproductive health care;

b. sufficient food and water; and

c. social security, including, if they are unable to support themselves and their dependents, appropriate social assistance.

2. The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights.

3. No one may be refused emergency medical treatment".

The right to access to health care and the right to life could also overlap, as the preservation of life is often dependant on the availability of health care resources. In the *Soobramoney*[388] case the applicant was a 41 year old diabetic who suffered from ischaemic heart disease and cerebro-vascular disease and as a result suffered a stroke. His condition was irreversible and he was in the final stages of renal failure. However, his life could be prolonged by obtaining regular renal dialysis. He requested the treatment from the Addington Hospital in Durban. The renal unit at Addington Hospital at the time had 19 dialysis machines in good working condition. Each treatment took four hours, whereas two additional hours had to be allowed between patients to allow for cleaning of the machines. Due to the limited facilities for kidney dialysis the hospital had been unable to provide the applicant with the treatment he required. Due to the shortage of resources the hospital followed a set policy with regard to the use of the dialysis machines in that only patients who suffered from acute renal failure which could be remedied by renal dialysis were given direct access to renal dialysis at the hospital. Patients who suffered from chronic renal failure which is irreversible (as in the case of the applicant) were not admitted automatically to the renal programme. The primary requirement for admission of these chronic patients was that the patient had to be

[388] *Soobramoney v Minister of Health, KwaZulu-Natal* 1998 (1) SA 765 (CC).

eligible for a kidney transplant. Furthermore, an applicant was not eligible for a transplant if he or she was not free of significant vascular or cardiac disease. The applicant in this case suffered from ischaemic heart disease and cerebro-vascular disease and was therefore not eligible for a kidney transplant. The applicant based his claim on Section 27(3) of the Constitution "No one may be refused emergency medical treatment" and Section 11 of the Constitution which states that "Everyone has the right to life".

Chaskalson, J remarked that:

> "We live in a society in which there are great disparities in wealth. Millions of people are living in deplorable conditions and in great poverty. There is a high level of unemployment, inadequate social security, and many do not have access to clean water or to adequate health services. These conditions already existed when the Constitution was adopted and a commitment to address them, and to transform our society into one in which there will be human dignity, freedom and equality, lies at the heart of our new constitutional order. For as long as these conditions continue to exist that aspiration will have a hollow ring".[389]

The Constitutional Court said that it was apparent from sections 26 (the right to housing) and section 27 (the right to health care, food, water and social security) that these obligations on the state were dependent on available resources and that the rights were limited by the lack of resources. The court further said that section 27(3) needed to be read in the context that given the lack of resources, an unqualified obligation to meet the needs would at the time be unable to be fulfilled. The court also remarked that the words "emergency medical treatment" could have included ongoing treatment of chronic diseases for the purpose of prolonging life. However, this was not their ordinary meaning, and if the purpose of section 27(3) was to serve ongoing chronic illness, one would have expected that to be expressly stated in positive and specific terms. The court said that for the applicant to be kept alive by dialysis would require treatments two

[389] *Soobramoney v Minister of Health, KwaZulu-Natal* 1998 (1) SA 765 (CC) at 8.

to three times a week and that section 27(3) did not apply to the facts of the case, since the applicant did not suffer from an emergency which called for immediate remedial action, but rather that it was an ongoing condition resulting from a deterioration of the applicant's incurable renal function. The court said that the Department of Health in KwaZulu-Natal did not have sufficient funds to cover the cost of the services which were being provided to the public and that there were many more patients nationwide requiring dialysis than there were machines to treat them. Therefore, agonising choices had to be made in terms of who received treatment and who did not and therefore the guidelines had been established. At Addington Hospital at the time the dialysis machines could handle only 60 patients but were treating 85, therefore it could barely treat the patients who met the guidelines. The court said that the applicant's case had to be seen in the context of the needs which the health services had to meet, and if treatment was provided to the applicant, it would have needed to be provided to others persons in similar positions.

The court per Chaskalson, J said that:

> "One cannot but have sympathy for the appellant and his family, who face the cruel dilemma of having to impoverish themselves in order to secure the treatment that the appellant seeks in order to prolong his life. The hard and unpalatable fact is that if the appellant were a wealthy man he would be able to procure such treatment from private sources; he is not and has to look to the state to provide him with the treatment. But the state's resources are limited and the appellant does not meet the criteria for admission to the renal dialysis programme. Unfortunately, this is true not only of the appellant but of many others who need access to renal dialysis units or to other health services".[390]

According to Hassim the *Soobramoney* case informs us that the right to access to health care service does not mean that the state is under a duty to provide all health

[390] *Soobramoney v Minister of Health, KwaZulu-Natal* 1998 (1) SA 765 (CC) at 31.

care services to everyone at once.[391] The lack of available resources meant that the state did not have to provide access to dialysis for Mr Soobramoney. According to Hassim the *Soobramoney* case "also teaches us that the reasonableness or otherwise of laws, policies and programmes is not just limited to their content. An otherwise reasonable policy may be implemented in an unreasonable manner. Justifiable laws, policies and frameworks are clearly only a starting point, albeit a very important one".[392]

2.4 Conclusions

Until such time as the legislature enacts legislation on contentious end-of-life issues such as the legal enforcement of living wills, euthanasia and assisted suicide, the courts are constitutionally obliged to give effect to a person's constitutional rights especially the rights to life, dignity and freedom and security of the person which includes the right to bodily and psychological integrity. Since dying is part of life, the right to life should include the right to die with dignity. It is obvious that the right to dignity, which includes the right to be treated as a human being, plays a very important role in end-of-life decisions, but ultimately it depends on the facts of each case to determine which rights should be given more weight than others in a specific instance. In a case where a person is, for example, suffering inhumanely and current palliative care is no longer sufficient to relieve pain and suffering, the right to dignity should ideally trump the right to life. Hospice movements are said to respect life when easing the process of dying and acknowledging that dying is part of life.[393] In the new Constitutional order, the purposive interpretation of the South African Constitution and the judgments of the Constitutional Court place a high premium on the right to life and the right to dignity which lead to for example the abolishing of the death penalty in the *Makwanyane*[394] case. The special emphasis on the rights to life and dignity in South Africa may be regarded as a consequence of the Apartheid human rights atrocities that took place,

[391] Hassim A, Heywood, M & Berger J *Health & Democracy* (2007) 36.
[392] Hassim A, Heywood, M & Berger J *Health & Democracy* (2007) 37.
[393] Carstens P & Pearmain D *Foundational Principles of South African Medical L*aw (2007) 28.
[394] *S v Makwanyane* 1995 (3) SA 391 (CC).

where the right to life and dignity were not respected and where some people were treated inhumanely. Foster stated that dignity is "the bioethical Theory of Everything",[395] and we should therefore utilise the right to dignity to solve end-of-life legal deficiencies.

It is clear that for the development of the legal position with regard to issues such as assisted suicide in South Africa, it will not be enough for the courts to develop the common law. The development of the common law is a cumbersome, time-consuming and costly way to develop the law. Also, while the common law is developing legal uncertainty will prevail, which will require further litigation. Comprehensive legislation should be developed on euthanasia or assisted suicide which will have to include comprehensive safeguards. A legal comparative study can be made of countries that have legalised assisted suicide such as Canada and the Netherlands and the safeguards that they have incorporated into their legislation can be scrutinised. In the *Hartmann*[396] case, even though in terms of sentencing the accused medical doctor received a suspended one year jail sentence, and was only detained until the rising of court, for assisting his father to die, the medical doctor was found guilty of murder by the court, thus obtained a criminal record, and the Medical Council took disciplinary steps against him, which are unfortunate consequences for the "mercy-killing" solely motivated by the best interests of the patient (his father). It will be an important aspect of any end-of-life legislation such as legislation on living wills to provide a framework to absolve medical practitioners from criminal and civil liability should they perform the instructions as contained in these documents such as pain management even if it should lead to the hastening of the death of the patient. The necessary safeguards and controls must of course be in place before medical practitioners can adhere to living will instructions. Since this thesis employs a broad understanding of living wills which may include any future health care instructions, not just refusals of medical treatment, potentially all the special circumstances discussed in chapter 5 and more, could in future when these special circumstances are legally permissible to be consented to in advance, apply. The special circumstances in chapter 5 include: do not resuscitate

[395] Foster C *Human Dignity in Bioethics and Law* (2011) 1-4.
[396] *S v Hartmann* 1975(3) SA 532 (C).

orders, emergency situations, permanent vegetative states, dementia, cessation of artificial hydration and feeding, pregnancy, euthanasia, palliative care and pain relief, as well as organ donation. Some of these circumstances are already of legal effect such as organ donation instructions and do not resuscitate orders. Other situations are more contentious and will depend on a factual enquiry to establish the legality of those actions. It is for example not possible to request assisted suicide in any advance directive at the moment because consent to assisted suicide or euthanasia does not legalise these acts.

Since living wills can ultimately be expanded to include circumstances such as those mentioned in chapter 5, thus for example the inclusion of euthanasia or assisted suicide directives, when euthanasia or assisted suicide are decriminalised, any legislation on living wills should be comprehensive and strict safeguards should apply.

The President is urged to handle any end-of-life legislation, including living will legislation, with great circumspection. In terms of section 79 of the Constitution "the President must either assent to and sign a Bill or, if the President has reservations about the constitutionality of the Bill, refer it back to the National Assembly for reconsideration". The President is advised to follow the procedure set out in section 79 in terms of which if necessary, after reconsideration of the proposed legislation, the President still has reservations, he can refer the draft legislation to the Constitutional Court for a decision on its constitutionality.[397] Should the Constitutional Court conclude that the Bill is constitutional, the President must then assent to and sign it.[398] This will prevent potential human rights issues that can arise from the legal enforcement of unconstitutional legislation. As the legal enforcement of any end-of-life and/or living will legislation will have serious life and death consequences, with grave impact on the discussed human rights, and thus public interest consequences, any proposed legislation should be well considered, detailed, contain safeguards, and all the relevant parties from the legal and medical fraternity, as well as the public, should be invited to

[397] S 79(4)(b) Constitution of the Republic of South Africa, 1996.
[398] S 79(5) Constitution of the Republic of South Africa, 1996.

comment and deliberate on these far-reaching proposals for legal reform. In chapter 3 the current legal status of living wills in South Africa are discussed and the draft legislation examined.

CHAPTER 3

THE CURRENT LEGAL STATUS OF THE ENFORCEABILITY OF LIVING WILLS IN SOUTH AFRICA

Outline

3.1 Introduction

This chapter focusses on the historical background to and current legal debate on living wills, advance directives and enduring powers of attorney in South Africa. The current draft legislation Draft Bill on End of Life Decisions and the National Health Amendment

Bill, 2019 (Private Member's Bill), the Health Professions Council of South Africa (HPCSA) guidelines and the South African Medical Association (SAMA) guidelines will be explored. The foundation for this chapter was provided in the previous chapter, which dealt with applicable human rights in the Bill of Rights, with reference to end-of-life decisions and living wills. This chapter primarily concerns the legal validity of a living will document in its entirety in South Africa. The drafting and legality of specific clauses in living wills regarding specific circumstances and specific medical conditions will not be discussed in this chapter, but in chapter 5. These specific circumstances, discussed in chapter 5, will include medical emergency situations, do-not-resuscitate orders, permanent vegetative states, dementia, cessation of artificial hydration and feeding, pregnancy, euthanasia and assisted suicide, palliative care and pain relief as well as organ donation. The legal validity of living wills in the Netherlands, England and Canada will be discussed in chapter 4. The relevant sources of International Law, which apply to the field of end-of-life decisions and living wills, are also discussed in chapter 4.

3.2 Definition of a Living Will under South African Law

Professor SA Strauss defines a living will as follows:

> "Legally [...] a declaration in which a person *in anticipando* by way of an advance directive refuses medical attention in the form of being kept alive by artificial means."[399]

According to SAMA a living will is described as:

> "…a declaration or an advance directive which will represent a patient's wish to refuse any medical treatment and attention in the form of being kept alive by artificial means when the patient may no longer be able to competently express a view".[400]

[399] Strauss SA *Doctor, patient and the law* (1991) 344. See chapter 1 para 1.1.2 re definitions of living wills.

[400] South African Medical Association "Living Wills and Advance Directives" (2012) <https://www.samedical.org/images/attachments/guidelines-with-regard-to-living-wills-2012.pdf> (accessed 31-07-2019).

Landman and Henley describe an advance directive (which may include a living will document) as:

> "…an instruction by a competent person regarding his or her medical or other health care decisions, which should be acted upon when he or she becomes incompetent and therefore unable to make such decisions".[401]

Although these instructions typically take on the form of an advance refusal of specific medical treatments, these instructions are not limited to advance refusals but can include a patient's requests, values and beliefs which should be taken into account by the medical practitioner when making a treatment decision or should be taken into account by the court, should a legal enforceability query be raised. This view supports the broad and inclusive concept of living wills that is employed in this thesis.

The Law Commission's Report describes the South African position as follows:

> "A so-called advance directive (living will) is drafted by a competent person who foresees the possibility that he or she may at some future date, as a result of physical or mental inability, be unable to make rational decisions as to his or her medical treatment and care. In this document the drafter therefore endeavours to make certain requests or issue directives to the people who would be responsible for his or her medical treatment. The underlying principle is that the patient has the right to refuse specific treatment, even life-sustaining treatment, and that medical staff are obliged to honour the wishes of the mentally competent patient. When a patient is no longer able to make decisions regarding his or her treatment or care, doctors are dependent on prior consent, directives by an agent or their own judgment, with due observance of the ethical code that binds them. The object of the advance directive (living will) is therefore to give guidelines to medical practitioners as to their conduct in circumstances where the patient is unable to do so himself or herself. It is a particular object of this document to

[401] Landman WA & Henley LD "Legalising advance directives in South Africa" (2000) *S Afr Med J* 90(8) 785-787.

absolve medical practitioners from liability should the treatment or the withholding of such treatment hasten the death of the patient."[402]

As noted in chapter 1, much confusion exists surrounding the terminology and meaning of "advance directives" and "living wills".[403] The concepts of "advance directives for health care" and/or "living wills" are described in different terms in different jurisdictions worldwide, and all these documents have different applicability criteria. Advance directives for health care are also referred to as "advance statements", "advance directives", "living wills", "*wilsverklaringen*", "*levenstestamente*", "personal directives", "personal requests", "advance decisions" or "advance requests".[404] The confusion surrounding the use of terminology with multiple definitions and therefore no standardised legal outcome, could ultimately lead to legal enforcement and liability problems. Even though all these documents have different applicability criteria, they do share a common feature in that they allow a maker to make his or her wishes known in advance, and/or they provide instructions in case of future mental incompetence or incapacity of the maker.

As mentioned in chapter 1, and the above paragraphs, in this thesis the broader definition of a living will is employed. In terms of this definition a living will could not only be utilised in the case of medical refusals for example to refuse treatment such as being kept alive by artificial means or do-not-resuscitate orders in specific circumstances, but could also be a document in which patients' medical requests and instructions are stipulated for active care to be implemented such as pain management instructions, instructions for specific medical situations and/or conditions which a patient might encounter, not only at the end of his or her life, but also during the course of his or her active life for example should he or she suffer from dementia as discussed in chapter 5.

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[402] South African Law Commission Report *Euthanasia and the artificial preservation of life Project 86* (1997) 156.
[403] See Chapter 1 para 1.1.2.
[404] See Chapter 4 para 4.3 for a discussion on advance directives and living wills in the Netherlands. See para 4.4 regarding advance directives and living wills England. See para 4.5 advance directives and advance requests for medical assistance in dying in Canada.

3.3 The Current Legal Position in South Africa

A living will (or advance directive) document is currently legally unenforceable in South Africa. One of the aims of this study is to provide a possible framework for the legal enforceability of living wills in South Africa. However, in practice there are different ways in which a patient's advance directives concerning his or her health care wishes and instructions can be approached, notwithstanding the legal uncertainty in this field. The first is *via* a living will or advance directive document. The second manner in which a patient can provide an advance directive is by way of a proxy directive. This is where a health care proxy is appointed in terms of an enduring power of attorney.[405] Living wills and enduring powers of attorney documents can also be written as one single document sometimes called "living will" or "advance directive" or given another name such as "advance wishes", "advance requests", "personal requests" or a similar term. As stated in chapter 1, the terminology anomaly or confusion that exists in the South African medical and legal fraternity is a result of the fact that there is currently no specific legislation on living wills, advance directives and enduring powers of attorney on health care in South Africa. Since these documents are also not recognised as part of our common law, there is thus no law specifically on the legal validity of living wills, advance directives and enduring powers of attorney for health care in South Africa. As neither living wills nor enduring powers of attorney are recognised by South African statute, McQuoid-Mason argues that a living will that reflects the current wishes of a patient should be recognised at common law (as advance refusals of medical treatment).[406] However, enduring powers of attorney cannot be recognised at common law as these instruments become invalid as soon as the patient becomes mentally incompetent.[407]

The proposed Bill on End of Life Decisions, 1997, was submitted to Parliament in 1999, but has to date not yet been debated before Parliament. The said draft Bill fails to

[405] See Chapter 5 para 5.3.2
[406] McQuoid-Mason D "Advance Directives and the National Health Act" (December 2006) 96 12 *SA Medical Journal* 1236-1237.
[407] McQuoid-Mason D "Advance Directives and the National Health Act" (December 2006) 96 12 *SA Medical Journal* 1236-1237.

regulate living wills and advance directives satisfactorily, as it only provides broad regulations and does not provide the necessary specific drafting, validity and enforceability frameworks.[408] This may lead to legal uncertainty and enforcement problems such as interpretation issues and problems in ascertaining the true intention of the patient.

The National Health Amendment Bill, 2019 (Private Member's Bill) which was introduced to provide a legal framework for living wills and enduring powers of attorney, was submitted to Parliament in February 2019. The Bill has subsequently lapsed in terms of the rules of Parliament. It is furthermore uncertain if the Bill will be reworked and resubmitted in future as the Member of Parliament who submitted the Bill, Deidre Carter lost her seat after the May 2019 National General Elections. The legal status of living wills, advance directives and enduring powers of attorney is therefore still uncertain; these documents have not yet been held to be legally enforceable in any court of law in South Africa or to the contrary these documents have also not been held to be legally unenforceable in South Africa. The courts have, however, ruled that a mentally competent patient has the right to refuse medical treatment.[409]

3.3.1 The National Health Act

Although living wills, advance directives and enduring powers of attorney for health care are currently not recognised by South African law and therefore not legally enforceable, the National Health Act[410] provides a mechanism to enable a patient to appoint a health care proxy before becoming mentally incompetent. The health care proxy can therefore make health care decisions on behalf of the patient. The National Health Act[411] requires that the mandate must be in writing[412] and that the patient must have had legal capacity

[408] See para 3.7.1 below.
[409] *Castell v De Greef* 1994 (4) SA 408 (C); *Phillips v de Klerk* 1983 (T) unreported discussed in PA Carstens & D Pearmain *Foundational Principles of SA Medical Law* (2007) 921.
[410] National Health Act, 61 of 2003.
[411] National Health Act, 61 of 2003.
[412] S 7(1)(a)(i) National Health Act, 61 of 2003.

at the time that he or she executed it.[413] According to McQuoid-Mason, this mandate applies to situations of temporary and permanent incapacity and could be used to appoint a surrogate decision maker for end-of-life issues.[414] The National Health Amendment Bill, 2019 contains legal guidelines for the appointment of such a surrogate decision maker.[415]

Section 7 of the National Health Act[416] states that:

> "1) Subject to section 8 [which states that "a user has the right to participate in any decision affecting his or her personal health and treatment…"],[417] a health service may not be provided to a user without the user's informed consent, unless –
>
> a) the user is unable to give consent and such consent is given by a person-
>
> i) mandated by the user in writing to grant consent on his or her behalf;"

It can be argued that it would be possible to "read in" or infer from this that the following will comply with the broad provisions of this section: "such mandate as given in writing in an advance directive, living will or enduring power of attorney", but this argument has not yet been tested by the courts.[418]

Section 7(1)(a)(ii) continues:

> "… or
>
> ii) authorised to give such consent in terms of any law or court order;"

This could in future be when legislation on advance directives, living wills and enduring powers of attorney, is enacted or where a court grants an order that such an advance directive or living will document or proxy's decision must be enforced.[419]

If the health care user was unable to consent and no person was mandated or authorised to provide the necessary consent, the National Health Act states that:

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[413] S 7(3) read with S7(a)(ii) National Health Act, 61 of 2003.
[414] McQuoid-Mason D "Advance Directives and the National Health Act" (2006) *SA Medical Journal* 1237.
[415] See para 3.7.2 for a discussion on the National Health Amendment Bill, 2019 (Private Member's Bill).
[416] National Health Act, 61 of 2003.
[417] The wording of S 8 was inserted here for ease of reference.
[418] My addition and reading in. See also McQuoid-Mason D "Advance Directives and the National Health Act" (December 2006) 96 12 *SA Medical Journal* 1236-1237.
[419] My addition and analysis. See also McQuoid-Mason D "Advance Directives and the National Health Act" (December 2006) 96 12 *SA Medical Journal* 1236-1237.

> "… a health service may not be provided to a user without the user's informed consent, unless- … the user is unable to give consent and no person is mandated or authorised to give such consent, and the consent is given by the spouse or partner of the user or, in the absence of such spouse or partner, a parent, grandparent, an adult child or brother or a sister of the user, in the specific order as listed".[420]

A hierarchy of possible consenting partners and family members is thus created. Where the health care user is unable to consent, the National Health Act further provides that the "provision of a health service without informed consent is authorised in terms of any law or court order".[421] The National Health Act clearly states that where there is a serious risk to public health, the user can also be treated without his or her informed consent:

> "… a health service may not be provided to a user without the user's informed consent, unless - … failure to treat the user, or group of people which includes the user, will result in a serious risk to public health".[422]

Emergency situations, which may arise and where health care users are not able to give consent, are also catered for in the National Health Act. Section 7(1)(e) states that:

> "a health service may not be provided to a user without the user's informed consent, unless - … any delay in the provision of the health service to the user might result in his or her death or irreversible damage to his or her health and the user has not expressly, impliedly or by conduct refused that service".[423]

The Act requires that "[a] healthcare worker must take all reasonable steps to obtain the user's informed consent".[424] "Informed consent" is here defined as "consent for the

[420] S 7(1)(b) National Health Act, 61 of 2003.
[421] S 7(1)(c) National Health Act, 61 of 2003.
[422] S 7(1)(d) National Health Act, 61 of 2003.
[423] S 7(1)(e) National Health Act, 61 of 2003.
[424] S 7(2) National Health Act, 61 of 2003.

provision of a specific health service given by a person with legal capacity to do so and who has been informed as contemplated as having **full knowledge**".[425]

The "full knowledge" requirement in Section 6 is defined as follows:

"1) Every healthcare provider must inform a user of –

a) the user's health status except in circumstances where there is substantial evidence that the disclosure of the user's health status would be contrary to the best interests of the user;

b) the range of diagnostic procedures and treatment options generally available to the user;

c) the benefits, risks, costs and consequences generally associated with each option; and

d) the user's right to refuse health services and explain the implications, risks, obligations of such refusal.

2) The healthcare provider concerned must, where possible, inform the user as contemplated in subsection 1 in a language that the user understands and in a manner which takes into account the user's level of literacy."

According to section 7 it is clear that these proxy mandates take precedence over the wishes of relatives or partners. Only when no person was mandated or authorised to give the requisite consent, can the consent be given by a spouse or partner. Only in the absence of a spouse or partner, can a parent, grandparent, an adult child or a brother or sister of the health care user, give the requisite consent, in this order. It is necessary to take cognisance of the common law development of the principle of informed consent as a defence to unlawful action, as many of the elements of informed consent were taken up in the National Health Act.

[425] My emphasis. S 7(3) National Health Act, 61 of 2003 read with the full knowledge requirement as explained in S 6 of the National Health Act, 61 of 2003.

3.4 Historical Development: Informed Consent

In could be argued that in South Africa, the concept of living wills is rooted in the common law doctrine of informed consent. The doctrine of informed consent entails that an autonomous human being is allowed to make decisions regarding medical treatment and whether he or she wants to proceed or does not want to proceed with the particular medical treatment.[426] For the doctrine of informed consent to apply, doctors need to inform their patients about the material risks and benefits of recommended treatment and the patient has to decide whether to undergo the treatment or not.[427]

The doctrine of informed consent is based on the legal rule that consent can be a defence to criminal and/or civil liability. Consent as a ground for justification in our law has a wide ambit. The notion that consent may render a *prima facie* unlawful act not unlawful, fits the justification ground of *volenti non fit iniuria*. The *volenti non fit iniuria* justification entails that the element of unlawfulness or wrongfulness of a crime or delict can be excluded. For consent to operate as a defence, the patient must have appropriately provided informed consent. The following requirements need to have been met:[428]

1. The action must be recognised by law, therefore it may not be *contra bones mores*.[429]
2. The consent must be given by a person capable in law of consenting, that is by someone who is capable of forming an intention or is capable of understanding what he or she consents to (the person must be capable of volition).[430]

[426] Van Oosten FFW *The Doctrine of Informed Consent in Medical Law* (1989) LLD Dissertation 13; Jordaan L "The legal validity of an advance refusal of medical treatment in South African law (part 1)" (2011) *De Jure* 35.
[427] Van Oosten FFW *The Doctrine of Informed Consent in Medical Law* (1989) LLD Dissertation 13-25; Jordaan L "The legal validity of an advance refusal of medical treatment in South African law (part 1)" (2011) *De Jure* 35.
[428] *Castell v De Greef* 1994 (4) SA 408 (C) at 425 citing Van Oosten FFW *The Doctrine of Informed Consent in Medical Law* (1989) LLD Dissertation 14-19; Jordaan L "The legal validity of an advance refusal of medical treatment in South African law (part 1)" (2011) *De Jure* 45. Neethling J, Potgieter JM & Visser PJ *Neethling's law of personality* (2005) 98-100.
[429] Neethling J, Potgieter JM & Visser PJ *Neethling's law of personality* (2005) 100.

3. The consenting party must have had knowledge and been aware of the nature of the extent of the harm or risk.[431]
4. The consenting party must have appreciated and understood the nature and extent of the harm or risk.
5. The consenting party must have consented to the harm or assumed the risk.
6. The consent must be comprehensive, that is extend to the whole treatment regime, inclusive of the consequences.
7. The consent must be clear and unequivocal.
8. The consent must precede the conduct in question.
9. The consent must be manifested externally to qualify as a legal act.
10. The consent must, as a rule, be granted by the plaintiff or complainant himself.
11. The conduct in question must fall within the limits of the consent given; that implies that it must not exceed the bounds of the consent given.

Should consent succeed as a defence to the conduct in question, an otherwise unlawful or wrongful act could amount to an act that is lawful from a legal viewpoint. However, in appropriate circumstances and if it can be made out on the specific facts of the case, an accused or defendant may succeed with an alternative defence of ignorance or mistake to exclude the fault element of the action. This would be the case where the accused or defendant was either completely unaware that consent was lacking or mistakenly believed that consent had been granted.

The court in *Castell v De Greef*[432] had to decide whether a medical practitioner had incurred liability for negligence as a result of his failure to warn his patient of the material risks and complications which might arise from a surgical operation or medical treatment. For a patient's consent to constitute a justification that excludes the wrongfulness of medical treatment and its consequences, the doctor is obliged to warn

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[430] Neethling J, Potgieter JM & Visser PJ *Neethling's law of personality* (2005) 98-100. *R v Taylor* 1927 CPD 16; *R v Sagaye* 1932 NPD 236.
[431] *Esterhuizen v Administrator Tvl* 1957 3SA 710 (T) 719.
[432] *Castell v De Greef* 1994 (4) SA 408 (C).

a patient, before obtaining his or her consent, of a material risk inherent in the proposed treatment. This forms part of the doctor-patient contractual relationship. A material risk would be where "a reasonable person in the patient's position, if warned of the risk, would be likely to attach significance to it"; or "if the medical practitioner is or should reasonably be aware that the particular patient, if warned of the risk, would be likely to attach significance to it".[433]

In terms of the South African common law, every patient has the right to refuse medical treatment.[434] In *Castell v De Greef*[435] the court confirmed that it is for the patient to decide whether he or she wishes to undergo an operation (the right to refuse medical treatment) which is an exercise of the patient's fundamental right to self-determination. The right to self-determination includes the right to bodily integrity, which relates to the doctrine of informed consent. Van Oosten describes the position as follows: "The fundamental principle of self-determination puts the decision to undergo or refuse a medical intervention squarely where it belongs, namely with the patient."[436]

A patient can always request withdrawal or withholding of treatment if he or she is mentally competent at the time the request is made. This would amount to a contemporaneous refusal of medical treatment. According to Dworkin "competence" can be used in a task-specific sense. A person may be more competent in making certain decisions and less competent in making others, depending on the complexity of the decisions.[437] Beauchamp and Childress discuss the determination of competence and incompetence as follows:

> "Above the threshold [of competence], we treat persons as equally competent; below the threshold we treat them as equally incompetent. Gatekeepers test to

[433] *Castell v De Greef* 1994 (4) SA 408 (C) at 426.
[434] *Castell v De Greef* 1994 (4) SA 408 (C).
[435] *Castell v De Greef* 1994 (4) SA 408 (C).
[436] Van Oosten FFW *The Doctrine of Informed Consent in Medical Law* 414.
[437] Dworkin R "Life past reason" in *Life's Dominion* (1993) 225.

determine who is above and who is below the threshold. Where we draw the line should depend on the particular tasks involved."[438]

Beauchamp and Childress refer to standards that can be employed to determine competence.[439] These standards are either used individually or in combination. The standards comprise the inability to express or communicate a preference or choice, the inability to understand one's situation and its consequences, the inability to understand relevant information, the inability to give a reason, the inability to give a rational reason, the inability to give risk or benefit-related reasons and the inability to reach a reasonable decision.[440]

In general, there is no difficulty when a patient who requests the withdrawal or withholding of treatment is mentally competent at the time he or she makes the request, since the law recognises a patient's contemporaneous decision to refuse medical treatment (informed refusal). Mentally competent patients are free to refuse medical treatment even if it would have the effect of hastening death.[441]

In *Phillips v De Klerk*,[442] the court rejected the professional-medical judgment principle and confirmed the principle of patient self-determination by recognising the patient's right to refuse medical treatment. *In casu* a patient, who was a Jehovah's Witness, refused a blood transfusion on religious grounds. The court recognised the patient's right to refuse a blood transfusion on religious grounds. It could be argued that by recognising the patient's right to refuse a blood transfusion, the court recognised the patient's right to choose to die (the right to patient autonomy).

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[438] Beauchamp TL & Childress JF *Principles of Biomedical Ethics* (2009) 114.
[439] Beauchamp TL & Childress JF *Principles of Biomedical Ethics* (2009) 114-115.
[440] Beauchamp TL & Childress JF *Principles of Biomedical Ethics* (2009) 114-115.
[441] Cf *Castell v De Greef 1994 (4) SA 408 (C); Stransham-Ford v Minister of Justice and Correctional Services and Others* 2015 (4) SA 50 (GP).
[442] *Phillips v de Klerk* 1983 (T) unreported discussed in PA Carstens & D Pearmain *Foundational Principles of SA Medical Law* (2007) 921.

If a doctor were to disregard the patient's refusal of treatment and proceed with medical treatment, the doctor could be held liable for assault.[443] In *Stoffberg v Elliott*[444] it was stated:

> "In the eyes of the law, every person has certain absolute rights which the law protects ... and one of those rights is the right of absolute security of the person. Nobody can interfere in any way with the person of another, except in certain circumstances ... Any bodily interference with or restraint of a man's person which is not justified in law, or excused in law, or consented to, is a wrong, and for that wrong the person whose body has been interfered with has a right to claim such damages as he can prove he had suffered owing to the interference."

Strauss argues that if medical personnel proceeded with medical treatment despite the patient's refusal, the court can be approached for the appointment of a *curator ad litem* who will be able to obtain an interdict against the doctor who had wanted to treat the patient against his or her wishes.[445]

In reality, patients can be viewed as vulnerable members of society and they may often not be knowledgeable enough or mentally competent to request specific courses of action with regard to medical treatment due to the nature of their current illness, or an underlying illness such as dementia or due to an accident that renders them mentally incompetent. The living will or advance directive can aid in this situation to provide prospective or advance decision making instructions concerning medical treatment and can, if a patient so chooses, also include the decision to refuse medical treatment. When patients are mentally competent to express their medical instructions contemporaneously, those instructions are given effect to, and the instructions contained in the living will are not enforced. It is thus only in a situation of mental incompetence that a living will becomes relevant. However, certain problems and uncertainties can arise when requests are made on behalf of mentally incompetent

[443] *Stoffberg v Elliott* 1923 CPD 148.
[444] *Stoffberg v Elliott* 1923 CPD 148.
[445] Strauss SA *Doctor patient and the law* (1991) 345.

patients who have expressed their wishes by means of a living will or other advance directive, or where an authorised person seeks to act on behalf of the patient in terms of a proxy directive such as an enduring power of attorney.[446] Conflicting views concerning the patient's wishes and the patient's best interest could be held. In instances where a doctor is uncertain about the applicability of the living will or advance directive, or the enduring power of attorney in the circumstances of the case, and whether to comply with either the living will and/or the enduring power of attorney, the doctor should be able to approach a court for guidance.[447] However, often in life-threatening or emergency circumstances these documents, if readily available, would have to be assessed in haste to determine the originality, applicability, legality and validity thereof, as immediate medical action might need to be taken. In such circumstances, it would not always be practical to first approach a court for guidance, as the patient might require immediate urgent medical care such as resuscitation. Section 7A(9) of the National Health Amendment Bill (Private Member's Bill) specifically refers to the use of a living will in emergencies. It reads as follows: "[a] living will does not preclude emergency care until a person's condition can be established and the applicability of a living will can be determined".[448]

The majority of common law elements of informed consent were thus taken up in the National Health Act.[449] In terms of the National Health Act,[450] a "user has the right to participate in any decision affecting his or her health and treatment".[451] If the informed consent is granted by another person, other than the user, such person must, if possible, consult with the user before giving the required consent. Even if the user lacks legal capacity to give informed consent, but is capable of understanding, he or she must receive the information mentioned in section 6 (see wording of the full knowledge requirement in par 3.3.1). Legal scholars agree that Sections 7 and 8 of the National

[446] S 7(b)(i) National Health Act, 61 of 2003.
[447] Cf *Clarke v Hurst NO and others* 1992 4 SA 630 (D).
[448] See discussion on the use of living wills in emergency situations in Chapter 5 para 5.5.
[449] National Health Act, 61 of 2003.
[450] National Health Act, 61 of 2003.
[451] See discussion in par 3.3.1 above.

Health Act 61 of 2003 may thus provide grounds for arguing that health care practitioners must honour advance directives in the form of enduring powers of attorney.[452] Section 8 of the National Health Act states that:

"(1) A user has the right to participate in any decision affecting his or her personal health and treatment.

(2) (a) If the informed consent required by section 7 is given by a person other than the user, such person must, **if possible**, consult the user before giving the required consent.

(b) A user who is capable of understanding must be informed as contemplated in section 6 even if he or she lacks the legal capacity to give the informed consent required by section 7.

(3) If a user is unable to participate in a decision affecting his or her personal health and treatment, he or she must be informed as contemplated in section 6 after the provision of the health service in question unless the disclosure of such information would be contrary to the user's best interest."[453]

McQuoid-Mason argues that section 7 provides a possible mechanism to overcome the common law position regarding enduring powers of attorney. In terms of the common law enduring powers of attorney become invalid when the patient who granted the power of attorney, becomes mentally incapacitated. Jordaan notes that the provisions of sections 7 and 8 of the National Health Act are unclear as section 8 is subject to section 7.[454] However, the words "if possible" are important. That means that the user does not have be consulted when the user is mentally incompetent, only "if possible" must such a consultation take place. Section 8(3) states that if the user is unable to participate in decisions affecting his or her health and treatment, the user must be given full information on the treatment received after the provision of the treatment. Jordaan

[452] Jordaan L "The legal validity of an advance refusal of medical treatment in South African law (part 1)" (2011) *De Jure* 39-40. McQuoid-Mason D "Advance Directives and the National Health Act" (December 2006) 96 12 *SA Medical Journal* 1236-1237.
[453] S 8 National Health Act, 61 of 2003.
[454] Jordaan L "The legal validity of an advance refusal of medical treatment in South African law (part 1)" (2011) *De Jure* 39-40.

argues since section 8(3) does not contain the wording "if possible", it could be argued that there is an expectation that the patient will not be in a permanent incompetent state and that the information should be relayed when he or she regains competence.[455]

Jordaan states that:

> "the act therefore contains provisions which, if interpreted broadly, could provide the basis for arguing that an advance directive in the form of an enduring power of attorney made by a patient while competent attains legal validity once the patient becomes incompetent. The question that arises is that, if such powers of attorney are legally enforceable instructions, should the same legal status not be afforded to advance directives in the form of "living wills"? Living wills are not expressly recognised in the act, but section 8(1) makes it clear that a health care user has the right to participate in any decision affecting his or her personal health and treatment. Does this mean that a decision to refuse medical treatment in the future has the same legal validity as a contemporaneous decision? In view of the absence of clear and express recognition at common law or statute of the legal status of advance directives, this remains an open question".[456]

As seen from the discussions above, informed consent is a thus a requirement for lawful medical interventions. During the performance of medical treatments, patients may run the risk of serious bodily harm or even death, but should the patients have granted their consent to the medical treatment, liability for the physical injury might be excused. That would be the case, should the physical injury be inflicted during the course of normal therapeutic medical operations or treatment.[457]

However, in emergency situations consent is not always obtained, as patients are not always *compos mentis* to grant the required consent. In those circumstances, should a

[455] Jordaan L "The legal validity of an advance refusal of medical treatment in South African law (part 1)" (2011) *De Jure* 39-40.
[456] Jordaan L "The legal validity of an advance refusal of medical treatment in South African law (part 1)" (2011) *De Jure* 39-40.
[457] Burchell J *Principles of Criminal Law* (2016) 201-211.

living will be obtainable, it should be scrutinised and acted upon. However, should the emergency personnel be uncertain as to the applicability or validity of the living will, emergency care should ensue.[458]

Meyers argues that a doctor fulfils a dual role.[459] The first role is to cure the patient. If the patient is in such a condition that he or she cannot be cured, then the doctor has the duty to relieve the patient's pain and suffering. Meyers distinguishes between "normal" and "abnormal" medical care. He describes "normal" care as care that can be measured against the standards of acceptable medical practice. "Abnormal" care goes beyond the standards of acceptable medical practice. Meyers believes that the patient is free to refuse normal medical care. Meyers however, also supports the view that should a patient request abnormal care, his request should be respected.[460] However, in the instance where abnormal care is requested, conflict may arise when the medical doctor is of the view that the abnormal care requested goes against the Hippocratic Oath.[461] Doctors who feel strongly that regular (normal) care should be administered in the circumstances may not accept the patient's refusal thereof. In these circumstances, doctors can approach the courts for a declaratory order that the care in question be authorised notwithstanding the patient's wishes. It is thus a judgement call that has to be made in such conflict situations in terms of which the interests of the patient and the doctor's Hippocratic Oath need to be weighed up.

In South African law informed refusal of medical treatment implies that a mentally competent person may even refuse medical treatment in circumstances where a consequence of the refusal may be to hasten death.

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[458] See discussion on the applicability of living wills in emergency situations in Chapter 5 para 5.5.
[459] Meyers DW *Medico-legal implications of death and dying: a detailed discussion of the medical and legal implications involved in death and/or care of the dying and terminal patient* (1981) 565.
[460] Meyers DW *Medico-Legal Implications of death and dying: a detailed discussion of the medical and legal implications involved in death and/or care of the dying and terminal patient* (1981) 566.
[461] Dörfling DF "Genadedood in die Strafreg – 'n regsfilosofiese en regsvergelykende perspektief" (1991) LLM Verhandeling 199.

South African law is clear that the positive act of hastening death, not mere adherence to a patient's informed refusal of medical treatment, but actively causing the death, by for example administering lethal dosages of medicine, is regarded as a criminal act which amounts to murder. In *R v Makali,* the court stated that:

> "The true enquiry is whether the deceased would have died when he did but for the doctor's unlawful act. If the enquiry gives the affirmative answer the doctor is responsible for the death because he caused it to take place when it did, that is to say hastened it."[462]

Our courts still have to rule on the "doctrine of double effect" in terms of which a doctor administers medicine for pain relief, but in effect hastens the death of the patient. The courts have not yet ruled on whether this action of the doctor, could be regarded as murder or culpable homicide. The courts have however found that the medical act which is performed with the aim to cause death (not pain relief), is still regarded as murder.[463]

Some jurists believe that the administering of medicine to relieve pain, but as a secondary effect results in the hastening of the patient's death, should not be a punishable crime.[464] Kahn shares the view about the South African law:

> "The doctor who, in genuinely and reasonably attempting to relieve the pain of the patient, indirectly hastens the death of the patient, is not guilty of murder, because his conduct was not unlawful".[465]

Strauss agrees with Kahn's point of view. He argues that even if the act is *prima facie* illegal, it is socially acceptable and thus justifiable before the law. The community accepts the act due to societal usefulness.[466] Strauss furthermore argues that:

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[462] *R v Makali* 1950(1) SA 340 (N) at 344.
[463] *S v Hartmann* 1975 3 SA 533 C. See discussion on assisted suicide and euthanasia in Chapter 5 para 5.10.
[464] Strauss SA *Doctor, patient and the law* (1991) 346; Kahn *Murder as a Fine Art in The Sanctity of Human Life* 1983 as described in Dörfling DF "*Genadedood" in die Strafreg – 'n regsfilosofiese en regsvergelykende perspektief*" (1991) LLM Verhandeling 113.
[465] Kahn *Murder as a Fine Art in The Sanctity of Human Life* 1983 as described in Dörfling DF "*Genadedood" in die Strafreg – 'n regsfilosofiese en regsvergelykende perspektief*" (1991) LLM Verhandeling 113.

> "As long as the doctor acts in good faith using the usual pain-relieving substances, in reasonable quantities, with the intent to relieve pain and not to kill, there will be no question of criminal or civil liability on his part."[467]

Therefore, the doctor cannot be found guilty of murder or culpable homicide. Dörfling argues that in a case like this a doctor can have *dolus eventualis*, but since the act is socially acceptable and useful, the act cannot not be found to be illegal and therefore the question of guilt is not relevant.[468]

Dörfling poses the question whether the doctor's action should not rather be adjudicated from the viewpoint of the patient's consent.[469] Should society accept the consent, the action would not be *contra bones mores*. The South African Law Commission extensively investigated this issue in its Report on Euthanasia and the Artificial Preservation of Life in 1998. Active euthanasia and mercy killings are both seen as murder under the South African law.[470] There is a clear distinction between active and passive euthanasia. "Active" euthanasia is where a person intentionally and actively participates in causing the death of another such as a terminally ill patient to end pain and suffering (for example by administering a fatal injection or dose of medicine).[471] This is unlawful and constitutes murder,[472] attempted murder[473] or culpable homicide, depending on the facts of the case.[474] However, where such a death was caused in an effort to alleviate pain and suffering of the deceased person while he

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[466] Strauss SA *Doctor, patient and the law* (1991) 346; Dörfling DF "*Genadedood" in die Strafreg – 'n regsfilosofiese en regsvergelykende perspektief*" (1991) LLM Verhandeling 114.
[467] Strauss SA *Doctor, patient and the law* (1991) 346.
[468] Dörfling DF "*Genadedood" in die Strafreg – 'n regsfilosofiese en regsvergelykende perspektief* (1991) LLM Verhandeling fn160 114.
[469] Dörfling DF "*Genadedood" in die Strafreg – 'n regsfilosofiese en regsvergelykende perspektief* (1991) LLM Verhandeling 114.
[470] See discussion of case law in Chapter 5 para 5.10.
[471] Carstens PA & Pearmain D *Foundational Principles of SA Medical Law* (2007) 203-207; *S v Hartmann* 1975 3 SA 532 (C).
[472] *S v Hartmann* 1975 3 SA 532 (C).
[473] *S v Smorenburg* 1992 (2) SACR 389 (C).
[474] See discussion of case law in Chapter 5 para 5.10.

or she was still alive, the courts tend to show great leniency when imposing sentence.[475] "Passive" euthanasia is where a person withdraws or withholds treatment from a terminally ill patient or a patient suffering from unbearable pain, and the patient dies as a result of nature taking its course.[476]

In the instance of voluntary euthanasia, the fact that a patient provided informed consent, will not always constitute a defence. It depends on the country-specific legislation. Worldwide, however, attitudes and perceptions of death and dying are changing as can be seen from the ongoing international debate and law changes in different countries. All over the world, individuals are approaching the courts in an attempt to effect law reform on assisted suicide and end-of-life decisions. In England, for example, the Noel Conway assisted suicide case attracted a great deal of media attention.[477] Conway applied for judicial review of the ban on assisted suicide. He was 67 years of age at the time of the application. He was and is still suffering from motor neuron disease. Conway argued that the ban on assisted suicide prevented him from ending his own life without protracted pain. He wanted to have the opportunity to be granted control over his death and a doctor to be allowed to grant him a prescription of lethal medicine to take, once it was deemed that he had less than six months left to live. Conway was unsuccessful in his appeals to the High Court and Supreme Court of Appeal.[478] The most recent challenge to decriminalise assisted dying in England was brought by Phil Newby, a 48-year-old man who suffers from motor neuron disease. We await to see the outcome of this case.[479]

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[475] Cf *S v Hartmann* 1975 3 SA 532 (C); *S v De Bellocq* 1975 3 SA 538 (T); *S v Marengo* 1991 2 SACR 43 (W).

[476] Carstens PA & Pearmain D *Foundational Principles of SA Medical Law* (2007) 203-207; *Minister of Justice and Correctional Services v Estate Late James Stransham-Ford* [2017] 1 All SA 354 (SCA) at 2.

[477] In *R (on the application of Conway) v Secretary of State for Justice* [2018] EWCA Civ 1431. See case discussion in para 4.4.5.2.2.4.

[478] See case discussion Chapter 4 para 4.4. Bowcott O "Terminally ill former lecturer challenges UK ban on assisted dying" (21 March 2017); BBC News "Terminally ill Noel Conway loses Supreme Court appeal" (27 November 2018) <https://www.bbc.com/news/uk-england-shropshire-46359845> (accessed 19-07-2019).

[479] Dying in Dignity "Terminally ill man Phil Newby launches new assisted dying case" (2 July 2019) <https://www.dignityindying.org.uk/news/terminally-ill-man-phil-newby-launches-new-assisted-dying-case/> (accessed 3-7-2019).

3.5 Ethical Guidelines

Both the South African Medical Association ("SAMA") and the Health Professions Council of South Africa ("HPCSA") have issued various guidelines applicable to the legal enforcement of living wills and advance directives.

3.5.1 HPCSA: Guidelines for Good Practice in Health Care Professions

The HPCSA provides general ethical guidelines for good practice in health care professions. The general ethical guidelines include that patients should be provided with information regarding their treatment and prognosis.[480]

The guidelines state *inter alia* that health care practitioners "should":

> "Give their patients the information they ask for or need about their condition, its treatment and prognosis.
>
> Give information to their patients in the way they can best understand it. The information must be given in a language that the patient understands and in a manner that takes into account the patient's level of literacy, understanding, values and belief systems.
>
> Refrain from withholding from their patients any information, investigation, treatment or procedure the health care practitioner knows would be in the patient's best interests.
>
> Apply the principle of informed consent as an on-going process.
>
> Allow patients access to their medical records".[481]

The guideline that the patient must be given the information regarding his or her condition, treatment and prognosis in a manner that the patient can "best understand" is

[480] HPCSA "Guidelines for good practice in the healthcare professions: General ethical guidelines for the healthcare professions" Booklet 1 (September 2016) <https://www.hpcsa.co.za/Conduct/Ethics> (accessed 22-06-2019) 8.

[481] HPCSA "Guidelines for good practice in the healthcare professions: General ethical guidelines for the healthcare professions" Booklet 1 (September 2016) <https://www.hpcsa.co.za/Conduct/Ethics> (accessed 22-06-2019) 5 3 1- 5 3 5 8.

of great importance to the drafting of living wills. Living wills should be drafted in plain language, which takes into account the patient's level of literacy, understanding, values and beliefs to ensure that the patient truly understands the implications of his or her well-considered instructions and can give informed consent. The language used must also be clear to medical personnel who will have to interpret and act on the instructions contained in the living will. The guideline on the access to medical records is also crucial. As discussed in chapter 5, it is submitted that patients' advance directives and living wills should be included in their medical records to ensure that they are readily available to improve the enforceability of these documents.[482]

3.5.2 HPCSA: Ethical Booklet on Informed Consent

The HPCSA has published detailed guidelines for informed consent.[483] Some of these will be discussed here. The move from the principle of medical paternalism to patient autonomy is clear in the guidelines which state that "[i]t is for the patient, not the health care practitioner, to determine what is in the patient's own best interests". Practitioners may recommend a treatment or a course of action to patients, but they must not put pressure on patients to accept their advice. The guidelines state that during discussions with patients, health care practitioners should provide a balanced view of the treatment options. The need for informed consent must be explained to the patient. The other guidelines for informed consent which are relevant to this study are discussed in chapter 5.

[482] See par 5.3.4 "Safekeeping of Living Wills" for a further discussion on including advance directives and living wills as part of your medical record.
[483] HPCSA "Guidelines for good practice in the healthcare professions: Seeking patients' informed consent: the ethical considerations" Booklet 4 (September 2016) <https://www.hpcsa.co.za/Conduct /Ethics> (accessed 22-06-2019).

3.5.3 SAMA: Guidelines on Informed Consent[484]

The South African Medical Association has published guidelines on informed consent, including:

> "…informed consent means that sufficient information is provided to the patient to make an informed decision and that the patient actually understands the information and the implications of acting on that information. Informed consent relates to a person's right to human dignity and autonomy. The medical practitioner has the duty to obtain the consent, as s/he is in a position to answer questions and provide further details".[485]

3.5.4 SAMA: Guidelines on Living Wills and Advance Directives

Since there is at present no specific law regarding the validity of living wills in South Africa, the South African Medical Association has published guidelines for medical practitioners when dealing with living wills.[486] These guidelines have therefore been designed to assist doctors who are "confronted" with a "living will".

The South African Medical Association defines a "living will" as "a declaration or an advance directive which will represent a patient's wish to refuse any medical treatment and attention in the form of being kept alive by artificial means when the patient may no longer be able to competently express a view".[487]

The SAMA guidelines state that "[a]ny person may refuse medical treatment even if such refusal will result in irreversible harm or death unless such treatment is sanctioned by law". The SAMA emphasises that a "living will" is not a will in the testamentary sense

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[484] South African Medical Association "SAMA guidelines and policies as approved by SAMA Board of Directors" <https://www.samedical.org/legal-governance/sama_guidelines> (accessed 14-07-2019).
[485] South African Medical Association "SAMA guidelines and policies as approved by SAMA Board of Directors" <https://www.samedical.org/legal-governance/sama_guidelines> (accessed 14-07-2019).
[486] South African Medical Association "Living Wills and Advance Directive" (2017) <https://www.samedical.org/files/guideline_living_wills_and_advance_directive.pdf> (accessed 23-07-2019).
[487] Compare other definitions of living wills chapter 1 para 1.1.2 and chapter 3 para 3.2.

of the word. The SAMA holds the view that a person must be over the age of medical consent and *compos mentis* to be able to make a living will. The SAMA states that the living will declaration will remain valid even if the maker becomes *non compos mentis*. The SAMA emphasises that this validity *proviso* differs to the validity *proviso* of a power of attorney. A power of attorney loses its applicability and authority once the person granting the power of attorney becomes mentally incompetent. As mentioned earlier in this thesis, that is precisely why an enduring power of attorney for health care needs to be adopted in South African law.[488]

The SAMA errs on the side of caution and states that doctors are advised to approach "living wills" with considerable circumspection and could obtain advice from them if necessary.

The SAMA prescribes the following guidelines:

The first guideline emphasises the ethical principle of *beneficence*.[489] A doctor is required to "offer to treat and to relieve suffering" and should "generally act in the best interests of his or her patients". The SAMA is very clear that "there shall be no exception to this principle" of beneficence "even in the case of incurable disease or malformation". The SAMA refers to the World Medical Association's declaration on terminal illness in its guidelines, namely: "A doctor may relieve suffering of a terminally ill patient by withholding treatment with the consent of the patient or his immediate family if the patient is unable to express his will. Withholding of treatment does not free the doctor from his obligation to assist the phase of his illness and a doctor shall refrain from employing any extraordinary means which would prove of no benefit for the patient".

The second guideline pertains to the refusal of medical treatment. This SAMA guideline emphasises that "all patients have a right to refuse treatment, which right should be respected". However, the SAMA states that the patient's refusal of medical treatment,

[488] See Chapter 5 paras 5.3.1 and 5.3.2.
[489] See Chapter 1 discussion on *beneficence* para 1.2.3.3

“does not imply or justify abandonment of the patient”. Doctors are instructed to offer “medical care in accordance with good medical practice”. In line with the notion of patient autonomy, the type of medical care should be appropriate in the circumstances and acceptable to the patient. The SAMA encourages doctors to discuss possible future “administration of unwanted treatment” in a “sensitive manner with patients who are anxious”.

The third guideline describes the use of an advance directive and states that a “written advance directive, in the absence of contrary evidence, shall be regarded as representing the patient’s expressed wish”. The SAMA emphasises that the “drafting of an advance directive is the patient’s responsibility” but recommends that advance directives “should be drafted in conjunction with medical advice and counselling”. The SAMA further advises that patients should discuss the specific terms of their advance directives on a continual basis with their medical practitioners.

The fourth guideline concerns the enforcement or honouring of advance directives under all circumstances. The SAMA states in terms of the fourth guideline that patients frequently have a perceived misconception about advance directives to refuse life-saving or life-sustaining treatment, as they may believe that it will be honoured under all circumstances. The SAMA emphasises that the reality of medical practice makes the honouring of these types of advance directives under all circumstances impossible. The SAMA states that if an advance directive is “specific to a particular set of circumstances the directive will have no force when these circumstances do not exist”. On the contrary “[i]f an advance directive is so general that it applies to all possible events that could arise, it could be viewed as too vague to give any definitive direction to the doctor”. The correct phrasing and careful consideration of the wording of an advance directive are thus imperative. The SAMA emphasises that in the case of too vague or too narrow or too specific instructions, doctors must rely on their professional judgement to reach a decision.

The fifth guideline states that it is the "responsibility of a patient" to ensure that the "existence of an advance directive" is "known to his or her family and to those who may be asked to comply with its provisions". The SAMA recommends "that individuals who made an advance directive, should consider wearing on their person an indication as to the location of the document and lodge a copy thereof at their medical practitioner(s) and/or family member(s)". The SAMA presses it upon doctors who are aware of the existence of such an advance directive, to "make all reasonable efforts to acquaint themselves with its contents". The SAMA, however, states that in an emergency, "the necessary treatment should not be delayed in anticipation of a document which is not readily available".

In the sixth guideline, the SAMA strongly recommends that patients "review their advance directives at regular intervals" and further recommends that "patients should rather destroy the existing advance directive documents if they so wish, instead of amending it". This will ensure that previous versions of advance directives, which the patient revoked or amended are not enforced. A "clean", clearly worded and unambiguous advance directive (in contrast to one with multiple edits and additions or alterations) will ensure that a patient's wishes are clear and thus easier to enforce. Time is of the essence in emergencies, therefore instructions should be legible and clear.

Guideline seven states that "doctors with a conscientious objection to withhold treatment in any circumstances are not obliged to comply with an advance directive but should advise the patient of their views and offer to step aside or transfer treatment and management of the patient's care to another practitioner". This guideline is similar to the South African abortion practice in terms of which a doctor with a conscientious objection to perform an abortion, can refer the patient's care to another doctor who would be willing to perform the abortion.[490]

[490] The Choice on Termination of Pregnancy Act, 92 of 1996 is silent on the aspect of conscientious objection but it can be inferred from the right to freedom of religion, belief and opinion as contained in s15 of the Constitution of the Republic of South Africa,1996. Ngwena C "Conscientious objection and legal abortion in South Africa: delineating the parameters" (2003) *Journal for Juridical Science* 28(1) 1-18.

The eighth guideline of the SAMA states that the "late discovery of an advance directive after life-prolonging treatment has been initiated is not sufficient grounds for ignoring it".

The HPCSA and SAMA have in addition to the abovementioned guidelines published other guidelines which can be relevant to the applicability and enforceability of living wills in specific medical circumstances, for example, the HPCSA guidelines for withholding and withdrawing treatment and the SAMA guidelines for medical practitioners on euthanasia. These and other ethical guidelines are discussed in chapter 5, paragraph 5.10.

3.6 Case Law

In South Africa, there is very little case law on living wills. To date, none of the South African courts have explicitly ruled on the validity of an advance directive or living will.[491] However, the existence of a living will document was briefly discussed in the *Clarke v Hurst*[492] case. The importance of the case is discussed below.

3.6.1 *Clarke v Hurst*

The *Clarke v Hurst*[493] case, which dates back to 1992, dealt with the dilemma of whether to withdraw life-prolonging treatment, specifically artificial feeding, from a mentally incompetent patient. Dr Clarke (the patient) had suffered a heart attack, which resulted in complete cessation of his breathing and heartbeat. However, his heartbeat was restored after resuscitation, but since he had been deprived of oxygen to the brain for a prolonged period, he had suffered severe and irreversible brain damage. As a result of this brain injury, he remained in a comatose state. He was unable to swallow and had to receive feeding through a naso-gastric tube. Dr Clarke had been a member

[491] Legal position as at 11 September 2019.
[492] *Clarke v Hurst NO and others* 1992 4 SA 630 (D).
[493] *Clarke v Hurst NO and others* 1992 4 SA 630 (D).

of the Voluntary Euthanasia Society and had signed a document headed “A living will” which was directed to his family, his physician and any hospital. It stated that if there was no reasonable expectation of his recovery from extreme physical or mental disability, he directed that he should be allowed to die and not be kept alive by artificial means and heroic measures. Dr Clarke (the patient) ordered in his living will that medication be mercifully administered to him if required to alleviate terminal suffering, even though this action might shorten his life. Dr Clarke’s living will was unfortunately only discovered after he had been subjected to life-sustaining measures. This situation continued for four years, after which he remained in a persistent vegetative state. At this point, Mrs Clarke applied to the court to be appointed as *curatrix personae* of her husband. She wished to obtain the power to authorise the discontinuation of any further medical treatment, including artificial feeding. She requested a declaratory court order to the effect that she would not be acting unlawfully if she were to withhold permission to medical treatment or if she were to authorise that artificial life-sustaining measures be discontinued, even if such discontinuance would end her husband’s life.

The court held that in South African law, a *curator personae* is under a legal duty to act in the best interests of a patient and not necessarily in accordance with the patient’s wishes. The court said that on the facts of this case, it could not be said that the applicant would not be acting in the best interest of the patient if she were to discontinue the artificial feeding regime.

The court did not venture an opinion on the legal validity of the living will, but did however take note of Dr Clark’s living will and the fact that he had previously spoken out in favour of passive euthanasia.

The court stated that:

> “It is indeed difficult to appreciate a situation, save where the patient is suffering unbearable pain or is in a vegetative state, where it would be in his best interests not to exist at all. The patient in the present case has, however, passed beyond

> the point where he could be said to have an interest in the matter. But just as a living person has an interest in the disposal of his body, so I think the patient's wishes as expressed when he was in good health should be given effect." [494]

The court held that the decision whether the discontinuance of the artificial feeding of the patient and his resultant death would be wrongful, depended on whether it would be reasonable to discontinue such artificial feeding if judged on the boni mores of society, and this decision would be premised on the quality of life which the patient retained. The court stated that it approached the issue with strong predilection for the preservation of life, which did not extend as far as requiring that life should be preserved at all costs, irrespective of its quality.

The court held that because the capacity of Dr Clarke's brain for cognitive and collative life had been destroyed and the destruction of this capacity was irreparable, "the brain has permanently lost the capacity to induce a physical and mental existence at a level which qualifies as human life".[495] This meant that "judged by society's legal convictions, the feeding of the patient does not serve the purpose of supporting human life as it is commonly known" and the applicant, if appointed as *curatrix,* would act "reasonably and would be justified in discontinuing the artificial feeding" and would therefore "not be acting wrongfully if she were to do so" notwithstanding that the implementation of her decision might hasten the death of the patient.[496] Dr Clarke was discharged after the artificial treatment was withdrawn and died at home (that would be four years after he had suffered the cardiac arrest).[497] This judgement was criticised on the point that the court did not recognise the patient's right to autonomy.[498] This criticism highlights the moral and ethical dilemma of the law in taking decisions on matters regarding the prolonging of human life when the quality of such life is questionable.

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[494] *Clarke v Hurst NO and others* 1992 4 SA 630 (D) at 660.
[495] *Clarke v Hurst NO and others* 1992 4 SA 630 (D) at 649.
[496] *Clarke v Hurst NO and others* 1992 4 SA 630 (D) at 649.
[497] Kling S "Advance directives: whose will be done?" (March 2015) *Current Allergy & Clinical Immunology* 28 1 44.
[498] Slabbert M & van der Westhuizen C "Death with dignity in lieu of euthanasia" (2007) 22 SAPR/PL 368.

3.7 Draft Legislation

3.7.1 The Draft Bill on End of Life Decisions

3.7.1.1 History of the Draft Bill on End of Life Decisions

In October 1991 the Living Will Society of South Africa (which is no longer in operation), which was known as SAVES (The South African Voluntary Euthanasia Society) at the time, approached the Law Commission of South Africa requesting the possibility of legislation on living wills for South Africa. The Law Commission not only approved the study on living wills, but after due consideration also decided to expand the research project to include other end of life issues such as the termination of life by euthanasia and the artificial preservation of life. Initially, the Commission only focussed on passive euthanasia and cessation of life. However, international developments at the time, as well as enquiries and input from respondents, made it clear to the Law Commission that it had to expand the project to include an investigation into active euthanasia.

The Law Commission battled with the question of whether there was a need for legislation on end of life decisions. The minority felt that legislation was not the appropriate instrument to deal with end of life decisions. However, it was eventually agreed that legislation would enhance the treatment of terminally ill and dying patients and recommended that formal legislation had to be put forward on all end of life issues. The Law Commission conducted research, drafted suggestions, invited feedback thereon and redrafted individual sections. The Law Commission's efforts resulted in the South African Law Commission's report addressing several end of life decision scenarios. The Law Commission's Report[499] included the final Draft Bill on End of Life Decisions which is discussed below. To date, no legislation has been enacted on these topics.

[499] The Law Commission Report which was published in November 1998, was preceded by "Discussion Paper 71" in 1997 and "Working Paper 53" in 1994.

3.7.1.2 Provisions of the Draft Bill on End of Life Decisions

The South African Law Commission in its Report on Euthanasia and the Artificial Preservation of Life[500] recommended that legislation should be enacted in South Africa to give effect to the following principles/situations/scenarios:

i) "A medical practitioner may, under specified circumstances, cease or authorise the cessation of all further medical treatment of a patient whose life functions are being maintained artificially while the person has no spontaneous respiratory and circulatory functions or where his or her brainstem does not register any impulse".

ii) "A competent person may refuse any life-sustaining medical treatment with regard to any specific illness from which he or she may be suffering, even though such refusal may cause death or hasten the death of such a person".

iii) "A medical practitioner or, under specified circumstances, a nurse may relieve the suffering of a terminally ill patient by prescribing sufficient drugs to control the pain of the patient adequately even though the secondary effect of this conduct may be the shortening of the patient's life".

iv) "A medical practitioner may, under specified circumstances, give effect to an advance directive or enduring power of attorney of a patient regarding the refusal or cessation of medical treatment or the administering of palliative care, provided that these instructions have been issued by the patient while mentally competent".

[500] South African Law Commission *Euthanasia and the artificial preservation of life Project 86 Report* (1998).

v) "A medical practitioner may, under specified circumstances, cease or authorise the cessation of all further medical treatment with regard to terminally ill patients who are unable to make or communicate decisions concerning their medical treatment, provided that his or her conduct is in accordance with the wishes of the family of the patient or authorised by a court order".

The South African Law Commission's Draft Bill on End of Life Decisions has been drafted with the aim to regulate end-of-life matters including the enforcement of living wills.[501]

Clause 6(1) determines that:

> "Every person above the age of 18 years who is of sound mind shall be competent to issue a **written directive** declaring that if he or she should ever suffer from a terminal illness and would as a result be unable to make or communicate decisions concerning his or her medical treatment or its cessation, medical treatment should not be instituted or any medical treatment which he or she may receive should be discontinued and that only palliative care should be administered".[502]

It is furthermore an option for the person as contemplated in sub-clause 6(1) to act as a principal and entrust any decision making regarding the medical treatment or the cessation of such treatment to a competent agent by way of a written power of attorney.[503] Clause 6(2) states that:

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[501] Draft Bill on End of Life Decisions as contained in the South African Law Commission *Euthanasia and the artificial preservation of life Project 86 Report* ("Draft Bill on End of Life Decisions"). Cf critique of the Draft Bill on End of Life Decisions in Fleischer T "End-of-life Decisions and the Law: A New Law for South Africa?" (2003) 21 1 *Continuing Medical Education* 20-25.

[502] My emphasis.
[503] Cl 6(2) Draft Bill on End of Life Decisions.

> "A person as contemplated in [clause 6(1) above] … shall be competent to entrust any decision-making regarding the treatment as contemplated in that subsection or the cessation of such treatment to a competent agent by way of a written power of attorney, and such power of attorney shall take effect and remain in force if the principal becomes terminally ill and as a result is unable to make or communicate decisions concerning his or her medical treatment or the cessation thereof."

Clause 6(3) further describes the proposed validity requirements for the proper execution of a living will or power of attorney. Clause 6(3) states that:

> "A directive contemplated in [sub-clause] (1) and a power of attorney contemplated in [sub-clause] (2) and any amendment thereof, shall be signed by the person giving the directive or power of attorney in the presence of two competent witnesses who shall sign the document in the presence of the said person and in each other's presence."

Clause 6(4) describes the specific instance where a person who is under guardianship, or in respect of whom a curator of the person (*curator personae*) has been appointed, becomes terminally ill and no instructions, that is no advance directives[504] or written powers of attorney[505] regarding his or her medical treatment or the cessation thereof, have been issued. In this specific instance the decision making regarding the patient's medical treatment or the cessation thereof shall, in the absence of any court order or the provisions of any other Act to the contrary, vest in such guardian or curator.

This power of attorney will come into effect and remain in force once the principal becomes terminally ill and as a result of the illness is unable to make or communicate decisions concerning his or her medical treatment or the cessation thereof.[506] This

[504] As contemplated in cl 6(1) Draft Bill on End of Life Decisions.
[505] As contemplated in cl 6(2) Draft Bill on End of Life Decisions.
[506] Cl 6(2) Draft Bill on End of Life Decisions.

special power of attorney therefore differs from the traditional power of attorney, which ceases to be enforceable when the grantor becomes incapacitated.

In terms of the formal execution of the documents, the Draft Bill on End of Life Decisions states that the living will and enduring power of attorney or any amendments to these documents should be signed by the maker in the presence of two competent witnesses.[507] These two competent witnesses are required to sign the document in the presence of the maker and in the presence of each other.[508]

It is important to note that it will not be unlawful to cease medical treatment as contemplated in clause 6(1) if it contributes to causing the patient's death or hastening the moment of death.[509]

The Draft Bill on End of Life Decisions furthermore specifies the standards of conduct expected from medical practitioners in compliance with advance directives by or on behalf of terminally ill persons.

Clause 7(1) states that:

> "No medical practitioner shall give effect to a directive regarding the refusal or cessation of medical treatment or the administering of palliative care which may contribute to the hastening of a patient's death, unless-
> (a) the medical practitioner is satisfied that the patient concerned is suffering from a terminal illness and is therefore unable to make or communicate considered decisions concerning his or her medical treatment or the cessation thereof; and
> (b) the condition of the patient concerned, as contemplated in paragraph (a), has been confirmed by at least one other medical practitioner who is not directly involved in the treatment of the patient concerned, but who is competent to

[507] Cl 6(3) Draft Bill on End of Life Decisions.
[508] Cl 6(3) Draft Bill on End of Life Decisions.
[509] Cl 8(4) Draft Bill on End of Life Decisions; Cl 7(6) Draft Bill on End of Life Decisions.

express a professional opinion on the patient's condition because of his expert knowledge of the patient's illness and his or her examination of the patient concerned."

A medical practitioner must first ascertain whether an advance directive is authentic and whether the person who issued the directive was competent when the directive was formulated, before giving effect to an advance directive.[510] If the advance directive is found to be authentic and the maker mentally competent at the time of drafting the advance directive, a medical practitioner should communicate the existence and content of the directive of the patient concerned, and subsequently his findings and intentions, as well as that of the other medical practitioner, to the relevant family members of the patient before giving effect to such an advance directive.[511]

Should a medical practitioner be uncertain as to the authenticity of an advance directive, or should he have doubts about its legality, he shall treat the patient concerned as set out in clause 8 which prescribes the conduct of a medical practitioner in the absence of a directive.[512]

Clause 8(1) determines that:[513]

"If a medical practitioner responsible for the treatment of a patient in a hospital, clinic or similar institution where a patient is being cared for, is of the opinion that the patient is in a state of terminal illness as contemplated in this Act and unable to make or communicate decisions concerning his or her medical treatment or its cessation, and his or her opinion is confirmed in writing by at least one other medical practitioner who has not treated the person concerned as a patient, but who has examined him or her and who is competent to submit a professional opinion regarding the patient's condition on account of his or her expertise

[510] Cl 7(2) Draft Bill on End of Life Decisions.
[511] Cl 7(3) Draft Bill on End of Life Decisions.
[512] Cl 7(4) Draft Bill on End of Life Decisions.
[513] Cl 8(1) Draft Bill on End of Life Decisions.

> regarding the illness of the patient concerned, the first-mentioned medical practitioner may, in the absence of any directive as contemplated in [clause] 6(1) and (2) or a court order as contemplated in [clause] 9, grant written authorisation for the cessation of all further life-sustaining medical treatment and the administering of palliative care only".

Before a medical practitioner may act as contemplated in clause 8(1), he or she needs to enquire whether such conduct would be in line with the wishes of the relevant family members of the patient, except if the medical practitioner is authorised to act in accordance with clause 8(1) by means of a court order as described in clause 9.[514]

The Draft Bill on End of Life Decisions states that a medical practitioner is required to record in writing what his or her findings are regarding the patient's condition and any measures taken by him or her in respect of the patient's condition.[515] The Draft Bill on End of Life Decisions states explicitly that the provisions contained in the Bill may not be interpreted as to "oblige a medical practitioner to do anything that would be in conflict with his or her conscience or any ethical code to which he or she feels himself or herself bound".[516] A medical practitioner is therefore not forced to proceed with any actions catered for in the Act, should these actions be in conflict with his or her conscience or ethical codes to which he or she is bound.

The Draft Bill on End of Life Decisions gives radical powers to the court to terminate treatment in the absence of a directive by the patient.[517] The court may for instance order that medical treatment be terminated if there is no directive by or on behalf of a terminally ill person, and if the patient is suffering from a terminal illness and is unable to make or communicate decisions concerning his or her medical treatment or its

[514] Cl 8(2) Draft Bill on End of Life Decisions.
[515] Cl 8(3) Draft Bill on End of Life Decisions.
[516] Cl 11 Draft Bill on End of Life Decisions.
[517] Sneiderman B & McQuoid-Mason DJ "Decision-making at the end of life: the termination of life-prolonging treatment, euthanasia (mercy-killing), and assisted suicide in Canada and South Africa" (2000) *CILSA* XXXIII 199.

cessation. Such an application for the cessation of medical treatment can be made by any interested party.[518] However, the court may not make this order without the knowledge of interested family members, and without their having been given the opportunity to be heard by the court.[519]

The court needs to be convinced of the medical facts that should be based on evidence of at least two medical practitioners who have expert knowledge of the patient's condition and who have personally examined and treated the patient, or who have informed themselves of the patient's medical history and have personally examined the patient.[520] A medical practitioner who gives effect to such a court order will not incur any civil, criminal or other liability whatsoever.[521] According to Sneiderman and McQuoid-Mason these extensive discretionary powers given to the court could cause hospital administrators who try to conserve limited valuable medical resources to apply to court to have persistent vegetative state patients whose prognoses are hopeless, removed from ventilators against the wishes of their families.[522] These authors are further of the opinion that as long as there is a good reason for the hospital administrators' applications, they should succeed.[523] The financial aspects regarding end-of-life decisions, particularly the access to health care, the availability of resources and limited funding create dilemmas for the implementation of living wills.

3.7.2 National Health Amendment Bill, 2019

The National Health Amendment Bill (Private Member's Bill) attempted to provide a legal framework for the legal enforcement of powers of attorney for health care and

[518] Cl 9(1) Draft Bill on End of Life Decisions.
[519] Cl 9(2) Draft Bill on End of Life Decisions.
[520] Cl 9(3) Draft Bill on End of Life Decisions.
[521] Cl 9(4) Draft Bill on End of Life Decisions.
[522] Sneiderman B & McQuoid-Mason DJ "Decision-making at the end of life: the termination of life-prolonging treatment, euthanasia (mercy-killing), and assisted suicide in Canada and South Africa" (2000) *CILSA* XXXIII 199.
[523] *Soobramoney v Minister of Health, KwaZulu-Natal* 1998 1 SA 765 (CC) in Sneiderman B & McQuoid-Mason DJ "Decision-making at the end of life: the termination of life-prolonging treatment, euthanasia (mercy-killing), and assisted suicide in Canada and South Africa" (2000) *CILSA* XXXIII 199.

living wills. The objects of the Bill were to amend the National Health Act "so that advance health care directives such as the living will and the durable power of attorney for health care are legally recognised" and to provide "legal certainty and legal enforceability regarding these directives".[524]

3.7.2.1 History of the National Health Amendment Bill, 2019

The National Health Bill, 2019 which was a Private Member's Bill, was introduced by private member Deidre Carter on 27 February 2019, but unfortunately lapsed in May 2019 in terms of the rules of Parliament when the new Parliament was elected.[525] Mrs Carter is no longer a Member of Parliament. We await to see whether a new draft of the Bill will be re-submitted to Parliament by another member of parliament, in future.

3.7.2.2 Provisions of the National Health Amendment Bill, 2019

In terms of the "Memorandum on the objects of the National Health Amendment Bill, 2019" the objects of the Bill are the following:

> "The National Health Amendment Bill, 2019 … will amend the [National Health Act] so that advance health care directives such as the living will and the durable power of attorney for health care are legally recognised, and that legal certainty and legal enforceability regarding these directives are provided for."

The following "background" was given for the drafting of the National Health Amendment Bill, 2019:

> ''Dying is a natural and inevitable part of life. Unless we die an unnatural death, we will go through a natural dying process. For some, it will be peaceful and

[524] Point 2 Memorandum on the Objects of the National Health Amendment Bill, 2019 attached to the National Health Amendment Bill.
[525] The National Health Amendment Bill, 2019 (Private Member's Bill) lapsed in terms of Rule 333(2) of the National Assembly. Cruywagen V "New draft assisted-suicide bill delayed by the election of Parliament" (20 June 2019) *Cape Argus* 1.

dignified; for others it will be filled with pain, distress and suffering. We do not know which it will be.

Any competent person may foresee the possibility of becoming incompetent when they enter the terminal phase of the dying process, and may wish to control their health care decision making as they are able to do when they are competent. Advance health care directives are designed to enable competent persons to express their preferences and give instructions about such possible future situations.

The National Health Act, 2003 (Act No. 61 of 2003) … does, to an extent, contain provisions regarding advance health care directives in that in one provision of the Act, a ‘‘living will’’ is inferred and in another, provision is made for the appointment of a substitute health care decision maker. However, it is argued that these provisions, while a step in the right direction, are inadequate for a number of reasons. These reasons, inter alia, include that a ‘‘living will’’ is not expressly recognised; the purpose, scope and format of these advance health care directives are not explicitly set out; it is not clear whether they may in certain circumstances be overridden by family or treating medical doctors; whether persons acting upon the directives are immune from civil and criminal prosecutions; and how to deal with a situation where two substitute decision-makers disagree about the treatment the patient should receive.”

Unfortunately, the National Health Amendment Bill, 2019 was not detailed enough to cover all the necessary aspects required by a comprehensive Bill on living wills. The National Health Amendment Bill, 2019 did not provide any mechanisms to resolve conflicts where “two substitute decision-makers disagree about the treatment the patient should receive” as was stated as an aim in the “background” to the Bill. As seen in par 3.3.1 The National Health Act[526] does refer to a patient’s right to refuse medical

[526] National Health Act, 61 of 2003.

treatment and a patient's right to appoint a proxy, but does not state anything further on the aspect of advance directives and proxy directives. Therefore it is unfortunate that this National Health Amendment Bill, 2019 was not formulated with more specifications to cover legal loopholes with a view to its practical implementation.

The National Health Amendment Bill, 2019 defines a "living will" as: "the instrument or document contemplated in [clause] 7B". Clause 7B reads as follows:

"7B (1) For purposes of section 7(1)*(e)*, any person who is—

(a) 18 years or older; and

(b) of sound mind,

may express his or her refusal, for any future potentially life-sustaining medical treatment or procedure when such person may no longer be competent to express such refusal, in a living will substantially in the form contained in Schedule 3.

(2) The potentially life-sustaining medical treatment or procedure contemplated in subsection (1) may include—

(a) artificial nutrition;

(b) artificial hydration;

(c) dialysis;

(d) any medication or drug, including antibiotics, administered through any method, including an IV tube; or

(e) life support of any kind."

The National Health Amendment Bill, 2019 creates an administrative burden and more duties for the treating doctor. The Bill states that:

"7B (3) A treating medical doctor, before giving effect to the living will referred to in subsection (1), must—

(a) satisfy himself or herself that, on the face of the facts before him or her—

(i) the medical condition of the maker of the living will is terminal and incurable and the maker is no longer competent to make or communicate decisions concerning his or her medical treatment or refusal thereof;
(ii) the maker of the living will is in a permanent vegetative state; or
(iii) the maker of the living will is completely and irreversibly unconscious;
(b) satisfy himself or herself, in so far as is reasonably possible, of the authenticity of the living will; and
(c) inform, where practicably possible, the maker of the living will's spouse or partner, or in the absence of such spouse or partner, the maker's parent, grandparent, an adult child or a brother or sister, in the specific order as listed, of the existence and content of the living will."

Clause 7B(a) which states that the treating doctor "must satisfy himself on the face of the facts before him" that "the medical condition of the maker of the living will is terminal and incurable", should be within the realm of the treating doctor's knowledge and expertise. However, to expect the treating doctor to determine that the maker "is no longer competent to make or communicate decisions concerning his or her medical treatment or refusal thereof" may be more time consuming especially in difficult cases where the maker is still in a position to communicate, but the competency of the maker is questionable.[527] In such cases, experts in psychiatric evaluations may have to be called in for an evaluation of a patient's competence. The clause 7B(c) legal requirement quoted above in terms of which the treating doctor should inform the family members, according to the listed hierarchy, of the existence and content of the living will, not only places a new administrative burden on the treating doctor, but will also delay decision making regarding treatment in emergency situations which could be detrimental to the patient. Therefore, the phrase "where practically possible" is very important. "[W]here practically possible" means that a treating doctor does in fact not have to contact the family members in an emergency when time is of the essence and immediate emergency treatment is required.

[527] Refer to discussion on mental competence or capacity and informed consent in Chapter 3 para 3.4 above.

The clause 7B(3)(b) requirement that the treating doctor "must … satisfy himself or herself, in so far as is reasonably possible, of the authenticity of the living will" is a very problematic section to implement practically. Since South Africa does not have a national database for advance directive or living will documents, it is my submission that one should be created in terms of future regulations attached to any future legislation on living wills.[528] It is also submitted that living wills should form part of a patient's medical records and that the same mechanisms used to convey organ donation instructions could be employed to convey the existence and content of a patient's living will.

In terms of drafting requirements, the National Health Amendment Bill, 2019 states that a "living will … and any amendment thereof, must be in writing and must be signed by the maker thereof and two competent witnesses, in one another's presence: Provided that one of the witnesses is not the spouse or partner of the maker or related to the maker by blood or adoption". For the purposes of the Bill "competent witness" means **"**a person of the age of 14 years or older who, at the time he or she witnesses a durable power of attorney for health care or a living will, is competent to give evidence in a court of law". See chapter 5 for a discussion on the drafting of living wills.

The National Health Amendment Bill, 2019 contains a section on the doctrine of double effect.[529] The Bill states that:

> "A living will containing the refusal, withdrawal or withholding of medical treatment, or the withholding or withdrawal of such medical treatment in accordance with such living will, will not be invalid or unlawful even though such refusal, withdrawal or withholding of medical treatment will hasten the natural death of the maker of the living will"[530]

and that

[528] See Chapter 5 para 5.3.4 on the safekeeping of living wills.
[529] See discussion in Chapter 5 para 5.10 on the doctrine of double effect.
[530] Cl 7A(5) National Health Amendment Bill, 2019 (Private Member's Bill).

> "The treating medical doctor who withholds or withdraws any medical treatment in accordance with a valid living will, will not be criminally or civilly liable even though such withholding or withdrawal might hasten or had hastened the natural death of the maker of the living will."[531]

No mention is made of the standard of care of the treating medical doctor in the withholding or withdrawing of the medical treatment. It cannot be said that the doctor will never be held liable criminally or civilly – there will always be a factual enquiry to ascertain whether the doctor (or hospital) had acted lawfully (without direct intent or negligence) and in a reasonable manner (as can be expected of a reasonable doctor) in the execution of his or her legal and ethical duties.

The Bill also states that a "living will … may not be overridden by any other person".[532] This serves to confirm patient autonomy, but in practice, there will be instances when it will be in the patient's best interests that a living will may be overridden. The Bill does not take into account a lapse in time from drafting to execution of the living will, and that the patient may have changed his or her mind in the meantime. There can be a change in the circumstances of the patient since drafting, such as new diagnoses or the improvement of his or her medical condition. Changed circumstances concerning the development of new medical treatments since the living will was drafted, may also be a factor to be considered. A court could be approached for a declaratory order in circumstances where medical practitioners are uncertain whether to enforce or override the wishes contained in a living will document.[533]

Clause 7A(8) of the Bill describes the instances in which a living will may be revoked:
"A living will … may be revoked at any time by the maker thereof by—

(a) a signed and dated letter of revocation;

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[531] Cl 7A(6) National Health Amendment Bill, 2019 (Private Member's Bill).
[532] Cl 7A(7) National Health Amendment Bill, 2019 (Private Member's Bill).
[533] See the *Clarke v Hurst* 1992 4 SA 630 (D) case discussion in para 3.6.1.

(b) physically destroying it and any copies thereof;
(c) an oral expression of his or her intent to revoke it; or
(d) means of a later executed living will which is materially different from the former document."

When a maker revokes his or her living will, it is important that whoever is responsible for the safekeeping of the living will, or has copies of the living will (the patient, doctor, hospital, family, friends, attorneys) must also indicate on their copies that it has been revoked or destroyed. If an electronic copy was stored on a database or register, the entry should be deleted. If a medical doctor incorporated the living will into the patient's medical records, the medical records need to be updated. See chapter 5 on the revocation of living wills where the law of succession is discussed and where it is indicated how the Wills Act[534] which provides the legal framework for testamentary wills, can help create a framework for the revocation of living wills.

Clause 7B(9) reads that a "living will does not preclude emergency care until a person's condition can be established and the applicability of a living will can be determined".[535]

The Bill explicitly states that "a maker of a living will may also choose to make a durable power of attorney for health care contemplated in [clause] 7A".

The Bill furthermore attempts to provide a legal framework for enduring powers of attorney named "durable power of attorney for health care". The relevant clauses are quoted below.

"7A. (1) …any person who is—
(a) 18 years or older; and
(b) of sound mind,

[534] Wills Act, 7 of 1953.
[535] See discussion on the use of living wills in emergency situations in Chapter 5 para 5.5.

may appoint and entrust any decision-making power regarding his or her future medical treatment to any adult person to act as his or her agent and mandate such agent to take any and all medical decisions, including decisions about withholding or withdrawal of any treatment, on behalf of such person, when he or she is no longer competent to make or communicate such medical decisions, by way of a durable power of attorney for health care substantially in the form contained in Schedule 2.

(2) The maker of the durable power of attorney for health care referred to in subsection (1) may mandate the agent therein to take medical decisions on behalf of the maker, including—

(a) to refuse any specific types of treatment on behalf of the maker due to religious or other reasons; or

(b) about donating any or all of the transplantable organs or tissues of the maker.

(3) The durable power of attorney for health care referred to in subsection (1), and any amendment thereof, must be in writing and must be signed by the maker thereof and two competent witnesses, in one another's presence: Provided that one of the witnesses is not the spouse or partner of the maker, or related to the maker by blood or adoption.

(4) The durable power of attorney referred to in subsection (1) will take effect and remain in force if the maker thereof becomes incompetent to make, or communicate, decisions concerning his or her medical treatment or the withholding or withdrawal thereof.

(5) Any decision taken by the agent referred to in subsection (1), in terms of the durable power of attorney for health care—

(a) must be informed by any medical advice from the medical doctor treating the maker of the durable power of attorney for health care referred to in subsection (1);

(b) must be informed by the values, principles and beliefs of the maker in so far as these are known to the agent, and where not known, such decisions must be taken in the best interests of the maker;

(c) must be taken while the agent is competent to make such decisions; and

(d) is final and may not be overridden by any other person.

(6) The durable power of attorney for health care referred to in subsection (1) may be revoked at any time by the maker thereof by—

(a) a signed and dated letter of revocation;

(b) physically destroying it and any copies thereof;

(c) an oral expression of his or her intent to revoke it; or

(d) means of a later executed durable power of attorney for health care which is materially different from the former document.

(7) A maker of a durable power of attorney for health care may also choose to make a living will contemplated in section 7B."

3.8 Conclusions

A living will is a valuable document for any person or patient as it comes into effect only when a patient who issued a legally valid living will previously, while still mentally competent, is later found to be mentally incompetent. Appropriate health care decisions, as described in the living will, can then be implemented. Even though living wills may not always be clear or specific enough to cover all eventualities, or on the other hand may be too specific, and since prognoses may be difficult to make, it is through these living will documents that incompetent patients are not only given a voice to make known their health care wishes and instructions, but by recognising the living will, their right to patient autonomy will be respected and unnecessary pain and suffering may be

avoided. Living wills are useful to medical personnel and family members who are faced with difficult medical and end-of-life decisions of a patient.

In South Africa, the legal status of living wills is currently most unsatisfactory.[536] A number of basic human rights of people with living wills may not be acknowledged, such as the right to life, right to dignity, right to privacy, right to equality, right to security of the person which includes the right to bodily and psychological integrity, freedom of religion, belief and opinion and the right to access to health care.[537] However, the National Health Act can be used as a foundation for the creation of detailed living will legislation as section 7 already refers to the appointment of a health care proxy. Section 7 specifically states that where the patient is unable to provide consent, consent can be given by a person mandated by the patient in writing, to grant the required consent on his or her behalf. In future this section of the Act can potentially be expanded to include the following: written instructions in an advance directive, living will or enduring power of attorney.

The National Health Amendment Bill, 2019 was an attempt to effect amendments to section 7 of the National Health Act. A new legal framework will serve to establish legal certainty and professional standards for medical personnel, thereby reconfirming the rights of patients.

In chapter 4, a legal comparative study of the legal frameworks of living wills and advance directives in the Netherlands, England and Canada will be made. The applicable International Law will also be discussed. This can inform possible developments in South Africa as far as law reform is concerned. Chapter 5 contains draft examples of living wills and the applicability of living wills in specific circumstances will be discussed.

[536] Legal position as at 11 September 2019.
[537] Cf Chapter 2 for discussion on Human Rights.

CHAPTER 4:

INTERNATIONAL AND COMPARATIVE LAW: NETHERLANDS, ENGLAND AND CANADA

Outline

4.1 Introduction

This chapter commences with a discussion of International Law applicable to end-of-life decisions regarding advance directives and living wills. The focus of the chapter is the legal and historical background of living wills and advance directives, the current legal debate and current legal frameworks relevant to living wills and advance directives in the foreign jurisdictions of the Netherlands, England and Canada. This chapter follows on from chapter 3 which dealt with the South African position regarding living wills and advance directives. In chapter 5 the drafting of living wills and the applicability of living wills in South Africa, with reference to specific circumstances, will be discussed.

4.2 International Law and Instruments

The following International Law applies to the field of living wills and end-of-life decisions. In many of these international conventions and declarations the rights to life and dignity are emphasised.

4.2.1 Universal Declaration of Human Rights

The Universal Declaration of Human Rights was adopted by the United Nations General Assembly on 10 December 1948. This was done as a result of the human rights violations that occurred during the Second World War, in particular as a result of the extensive loss of life of people whose human rights were violated during the war. The Universal Declaration of Human Rights (1948) states unequivocally in its first article that:

> "All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood."[538]

Article 3 of the Universal Declaration of Human Rights emphasises that every person "has the right to life, liberty and security of person". Article 1 and article 3 of the Universal Declaration therefore provide a clear basis for the right to freedom, liberty, equality, life, security of the person and dignity which together form the foundation for the right to autonomy and thus the ability to make autonomous medical decisions.

4.2.2 European Convention on Human Rights

The European Convention on Human Rights was drafted in 1950 by the Council of Europe with its aim to provide an international convention to protect human rights and political freedom in European countries.

Article 2 of the European Convention for the Protection of Human Rights and Fundamental Freedoms states that everyone's right to life shall be protected by law and that no one shall be deprived intentionally of his life. Article 2, the right to life, reads as follows:

> "1. Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.
> 2. Deprivation of life shall not be regarded as inflicted in contravention of this article when it results from the use of force which is no more than absolutely necessary:
> (a) in defence of any person from unlawful violence;

[538] United Nations "Universal Declaration of Human Rights" <https://www.un.org/en/universal-declaration-human-rights/> (accessed 11-08-2019).

(b) in order to effect a lawful arrest or to prevent the escape of a person lawfully detained;

(c) in action lawfully taken for the purpose of quelling a riot or insurrection."

Article 8 states that:

"1. Everyone has the right to respect for his private and family life, his home and his correspondence.

2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others."

In the *Pretty*[539] decision the European Court of Human Rights interpreted article 2, the right to life, and article 8, the right to respect for private life, of the European Convention in connection with assisted suicide.

The Dutch legal expert Leenen discusses the possible conflict between the practice of euthanasia and article 2 of the European Convention. According to Leenen it has been argued that permitting the practice of euthanasia is in conflict with article 2 However, Leenen does not personally believe that the practice of euthanasia is in fact in conflict with article 2, for he explains that the European Convention focusses on individual, classical human rights. These rights are there to protect the rights of individuals against possible unwanted violations by the state. Furthermore, states have a positive obligation to see to it that the rights of its citizens are not violated. The rights contained in the European Convention are therefore not aimed at restricting the freedom of individuals. When a patient in the Netherlands requests euthanasia, this request must be brought by

[539] *Pretty v United Kingdom* (2002) 35 EHRR 1. See *Pretty* case discussion in para 4.4.5.2.2.1.

the patient himself.[540] The conditions for administering euthanasia to take place, have to be in line with article 2. Leenen states that:

> "A law on euthanasia which allows doctors to help an unbearably agonizing patient who begs for euthanasia when there is no alternative available to soften the suffering of the patient, is not contrary to the respect of life on which Article 2 is based. In the Dutch law the explicit and freely made request of the patient is conditional and requirements of due care to be followed are laid down in it. In principle it is left to the states how they protect the rights of the Convention. If a person is of the opinion that the state does not fulfill (sic) its obligation, he can go to the court, at the end the European Court of Human Rights."[541]

4.2.3 Council of Europe Recommendation: Principles Concerning Continuing Powers of Attorney and Advance Directives for Incapacity

In 2009, nearly six decades after the European Convention of Human Rights was published, the Council of Europe put forward a Recommendation named: "Principles concerning continuing powers of attorney and advance directives for incapacity".[542] This Recommendation was adopted by the Committee of Ministers of the Council of Europe on 9 December 2009. The Recommendation is addressed to all member states and provides guidelines for member states to reform their national legislation to bring it in line with the provisions contained in the Recommendation.

It is clear from the content of the Recommendation that the focus shifted from general principles of human rights law to include specific guidelines for advance medical decision making such as continuing powers of attorney and advance directives for incapacity.

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[540] See van Delden and discussion on euthanasia directives in para 4.3.1.2.2.
[541] Leenen HJJ "The Development of Euthanasia in the Netherlands" (2001) *European Journal of Health Law* 8 130. See discussion on euthanasia in the Netherlands in paragraph 4.3.
[542] Recommendation CM/Rec (2009)11 adopted by the Committee of Ministers of the Council of Europe on 9 December 2009 as proposed by the Committee of Expert on Family Law (CJ-FA) and supported by the European Committee on Legal Co-operation.

The European Court of Human Rights has referred to this Recommendation in its judgments.[543] The European Court of Human Rights found in the *Shtukaturov v Russia*[544] that:

> "Although these principles [of the Recommendation No R (99)4] have no force of law for this Court, they may define a common European standard in this area."

In the Explanatory Memorandum to the Recommendation the need for the existence of the Recommendation is amplified:

> "Experience at both national and international level in recent decades shows that the issue of adults with incapacity is arguably the most topical issue of family law at present; this may also prove to be true in years to come. Despite the overall improvement in the protection of human rights, this area of law was underdeveloped or even completely neglected in a number of member states."[545]

Furthermore, the Explanatory Memorandum states that:

> "It should be borne in mind that the numbers of elderly people are rising steadily in Europe, due to an overall improvement of living conditions, demographic and social changes and medical advances. However, the mental faculties of the elderly often decline with age and the number of persons suffering from diseases such as senile dementia or Alzheimer's disease is increasing throughout Europe. In addition, groups other than the elderly may also experience impairments of capacity."[546]

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[543] *H.F. v. Slovakia* 8 November 2005 (Application No 54797/00); *Shtukaturov v. Russia* 27 March 2008 (Application No 44009/05); *X v. Croatia* 17 July 2008 (Application No 11223/04).
[544] *Shtukaturov v Russia* (2008) ECHR 223.
[545] Par 10 of the Explanatory Memorandum to the Recommendation CM/Rec (2009)11 adopted by the Committee of Ministers of the Council of Europe on 9 December 2009 as proposed by the Committee of Expert on Family Law (CJ-FA) and supported by the European Committee on Legal Co-operation.
[546] Par 11 of the Explanatory Memorandum to the Recommendation CM/Rec (2009)11 adopted by the Committee of Ministers of the Council of Europe on 9 December 2009 as proposed by the Committee of Expert on Family Law (CJ-FA) and supported by the European Committee on Legal Co-operation.

The Explanatory Memorandum stresses that before the Recommendation was made, there had been "no instrument at the European level which provide[d] guidance for member states in the reform of laws allowing provisions to be made for future incapacity". This "new international instrument" was thus viewed as "relevant and timely" as "it could benefit the lives of many citizens who might wish to plan for their own possible future incapacity with the help of an instrument of legal nature, which might provide added value".[547]

The Recommendation refers to two anticipatory measures by which adults can achieve self-determination for the times when they would lack decision making capacity. The first is the continuing power of attorney and the second an advance directive.

The Appendix to the Recommendation explains that "States should [not only] promote self-determination for capable adults in the event of their future incapacity, by means of continuing powers of attorney and advance directives", but should also "in accordance with the principles of self-determination and subsidiarity […] consider giving those methods priority over other measures of protection".[548]

4.2.3.1 The Continuing Power of Attorney as described in the Recommendation

A "continuing power of attorney" is defined as "a mandate given by a capable adult with the purpose that it shall remain in force, or enter into force, in the event of the granter's incapacity". The "granter" is "the person giving the power of attorney" and the "attorney" is defined as "the person mandated to act on behalf of the granter".

The relevant sections of the Appendix to the Recommendation are:
"Part II Continuing powers of attorney

[547] Par 13 of the Explanatory Memorandum to the Recommendation CM/Rec (2009)11 adopted by the Committee of Ministers of the Council of Europe on 9 December 2009 as proposed by the Committee of Expert on Family Law (CJ-FA) and supported by the European Committee on Legal Co-operation.
[548] Principle 1 Promotion of self-determination Paras 1 and 2 of the Appendix to Recommendation CM/Rec (2009)11 8.

Principle 3 Content

States should consider whether it should be possible for a continuing power of attorney to cover economic and financial matters, as well as health, welfare and other personal matters, and whether some particular matters should be excluded.

Principle 4 Appointment of attorney

1. The granter may appoint an attorney any person whom he or she considers to be appropriate.
2. The granter may appoint more than one attorney and may appoint them to act jointly, concurrently, separately, or as substitutes.
3. States may consider such restrictions as are deemed necessary for the protection of the granter.

Principle 5 Form

1. A continuing power of attorney shall be in writing.
2. Except in states where such is the general rule, the document shall explicitly state that it shall enter into force or remain in force in the event of the granter's incapacity.
3. States should consider what other provisions and mechanisms may be required to ensure the validity of the document.

Principle 6 Revocation

A capable granter shall have the possibility to revoke the continuing power of attorney at any time.

Principle 7 Entry into force

1. States should regulate the manner of the entry into force of the continuing power of attorney in the event of the granter's incapacity.

2. States should consider how incapacity should be determined and what evidence should be required.

Principle 8 Certification, registration and notification

States should consider introducing systems of certification, registration and/or notification when the continuing power of attorney is granted, revoked, enters into force or terminates.

Principle 9 Preservation of capacity

The entry into force of a continuing power of attorney shall not as such affect the legal capacity of the granter.

Principle 10 Role of the attorney

1. The attorney acts in accordance with the continuing power of attorney and in the interests of the granter.
2. The attorney, as far as possible, informs and consults the granter on an ongoing basis. The attorney, as far as possible, ascertains and takes account of the past and present wishes and feelings of the granter and gives them due respect.
3. The granter's economic and financial matters are, as far as possible, kept separate from the attorney's own.
4. The attorney keeps sufficient records in order to demonstrate the proper exercise of his or her mandate.

Principle 11 Conflict of interest

States should consider regulating conflicts of the granter's and the attorney's interests.

Principle 12 Supervision

1. The granter may appoint a third party to supervise the attorney.

2. States should consider introducing a system of supervision under which a competent authority is empowered to investigate. When an attorney is not acting in accordance with the continuing power of attorney or in the interests of the granter, the competent authority should have the power to intervene. Such intervention might include terminating the continuing power of attorney in part or in whole. The competent authority should be able to act on request or on its own motion.

Principle 13 Termination

1. States should consider under which circumstances a continuing power of attorney ceases to have effect.
2. When a continuing power of attorney ceases to have effect in part or in whole the competent authority should consider which measures of protection might be taken."

It should be clear that a continuing power of attorney is drafted and executed when the patient is still mentally competent in order to plan for future mental incompetence.[549]

4.2.3.2 Advance Directives as described in the Recommendation

In the Recommendation[550] an "advance directive" is described as comprising "instructions given or wishes made by a capable adult concerning issues that may arise in the event of his or her incapacity".

The following Principles contained in the Appendix to the Recommendation pertain to advance directives:

"Principle 14 Content

[549] The discussion on competence and incompetence in para 3.4 should thus be read in tandem with para 4.2.3.1.
[550] See para 4.2.3.

Advance directives may apply to health, welfare and other personal matters, to economic and financial matters, and to the choice of guardian, should one be appointed.

Principle 15 Effect

1. States should decide to what extent advance directives should have binding effect. Advance directives which do not have binding effect should be treated as statements of wishes to be given due respect.

   States should address the issue of situations that arise in the event of a substantial change in circumstances.

Principle 16 Form

1. States should consider whether advance directives or certain types of advance directives should be made or recorded in writing if intended to have binding effect.
2. States should consider what other provisions and mechanisms may be required to ensure the validity and effectiveness of those advance directives.

Principle 17 Revocation

An advance directive shall be revocable at any time and without any formalities."

4.2.4 World Medical Association Declaration of Venice on Terminal Illness

The 35th World Medical Association General Assembly was held in Venice, Italy, in October 1983. At this assembly a declaration on terminal illness was formulated. The Declaration of Venice on Terminal Illness was later revised by the 57th World Medical Association General Assembly at Pilanesberg, South Africa in October 2006.

In the Preface to the Declaration of Venice it is stated that the ethical issues associated with end-of-life care, are inevitably accompanied by questions regarding the ethics of euthanasia and physician assisted suicide. The World Medical Association's policy condemns both euthanasia and physician assisted suicide as unethical practices.

In the Preamble the World Medical Association explains that:

> "When a patient's medical diagnosis precludes the hope of health being restored or maintained, and the death of the patient is inevitable, the physician and the patient are often faced with a complex set of decisions regarding medical interventions. Advances in medical science have improved the ability of physicians to address many issues associated with end-of-life care. However, it is an area of medicine that historically has not received the attention it deserves. While the priority of research to cure disease should not be compromised, more attention must be paid to developing palliative treatments and improving the ability of physicians to assess and address the medical and psychological components of symptoms in terminal illness. The dying phase must be recognized and respected as an important part of a person's life. As public pressure increases in many countries to consider physician assisted suicide and euthanasia as acceptable options to end suffering in terminal patients, the ethical imperative to improve palliative treatment in the terminal phase of life comes into sharp focus."

It further recognises that there are different attitudes and beliefs towards death and dying. People of different cultures and religions for instance have different attitudes to death and dying. Furthermore, the World Medical Association accepts that "many palliative and life-sustaining measures require technologies and/or financial resources that are simply not available in many places. The approach to medical care of the terminally ill will be influenced significantly by these factors, and thus attempting to developing (sic) detailed guidelines on terminal care that can be universally applied is neither practical nor wise."

The core principles which were formulated to assist physicians and National Medical Associations with decision making relating to end-of-life care, are summarised as follows:

1. Physicians must heal patients and relieve their suffering, protect their best interests, even in the event of an incurable disease.

2. Physicians have the responsibility to assist patients to experience quality of life and to address their needs, even to enable patients to die with dignity and in comfort. Patients should be informed of the availability, the benefits and side-effects of palliative care.

3. Physicians must respect a patient's right to autonomy in decision making with regard to making decisions during the terminal phase of life. The World Medical Association states that "This includes the right to refuse treatment and to request palliative measures to relieve suffering but which may have the additional effect of accelerating the dying process. However, physicians are ethically prohibited from actively assisting patients in suicide. This includes administering any treatments whose palliative benefits, in the opinion of the physician, do not justify the additional effects."

4. All treatment provided by the physician should be beneficial to the patient.

The World Medical Association Declaration of Venice on Terminal Illness states that doctors are morally obliged to act upon living wills and advance directives. Principle 5 of the Convention of Venice on Terminal Illness provides as follows:

> "5. Physicians should recognise the right of patients to develop written advance directives that describe their wishes regarding care in the event that they are unable to communicate and that designate a substitute decision-maker to make decisions that are not expressed in the advance directive. In particular, physicians should discuss the patient's wishes regarding the approach to life-

sustaining interventions as well as palliative measures that might have the additional effect of accelerating death. Whenever possible, the patient's substitute decision-maker should be included in these conversations."

6. Physicians should help patients and their families to work through psycho-social and spiritual issues such as anxiety, fears and trauma associated with terminal illness.

7. Pain management in terminal patients should be optimal and physicians should even be able to use appropriate and aggressive pain management procedures without fear of legal repercussions.

8. Governments and research institutions should receive enough resources to develop high-value end-of-life care. End-of-life care should feature in medical curricula.

9. Networks among institutions and organisations involved in palliative care, should be developed.

10. As far as the harvesting of organs for transplantation is concerned: "Physicians may, when the patient cannot reverse the final process of cessation of vital functions, apply such artificial means as are necessary to keep organs active for transplantation."[551]

4.2.5 World Medical Association: Declaration on the Rights of the Patient

The World Medical Association ("WMA") Declaration of Lisbon on the Rights of the Patient opens with the statement: "The relationship between physicians, their patients

[551] "Provided that they act in accordance with the ethical guidelines established in the World Medical Association Declaration of Sydney on the Determination of Death and the Recovery of Organs." (Principle 10).

and broader society has undergone significant changes in recent times. … While a physician should always act according to his/her conscience, and always in the best interests of the patient, equal effort must be made to guarantee patient autonomy and justice."[552] The WMA Declaration further states that the patient has the right to self-determination, to make free autonomous decisions regarding himself or herself and the physician will inform the patient of the consequences of his or her decisions.

The WMA Declaration states that a "mentally competent adult patient has the right to give or withhold consent to any diagnostic procedure or therapy" and the "right to the information necessary to make his [or] her decisions". A patient should have full knowledge of the purpose of any test or treatment, what the results mean, and what the implications would be, if consent is withheld. The WMA Declaration further states that should a patient be "in an unconscious state or otherwise unable to express his or her will, the physician's duty is to obtain informed consent, whenever possible, from a legally entitled representative". Should the "legally entitled representative" not be available, but a medical intervention urgently needed, the patient's consent may be presumed, "unless it is obvious and beyond any doubt on the basis of the patient's previous firm expression or conviction that he [or] she would refuse consent to the intervention in that situation". The Declaration confirms however that "physicians should always try to save the life of a patient [who is] unconscious [as a result of] … a suicide attempt".

If the patient is legally incompetent such as a minor or otherwise legally incompetent, "the consent of a legally entitled representative is required in some jurisdictions". Regarding the decision making process the Declaration states that: "Nevertheless the patient must be involved in the decision making to the fullest extent allowed by his [or]

[552] World Medical Association "Declaration of Lisbon on the Rights of the Patient" Adopted by the 34th World Medical Assembly, Lisbon, Portugal, September/October 1981 and amended by the 47th WMA General Assembly, Bali, Indonesia, September 1995 and editorially revised by the 171st WMA Council Session, Santiago, Chile, October 2005 and reaffirmed by the 200th WMA Council Session, Oslo, Norway, April 2015 <https://www.wma.net/policies-post/wma-declaration-of-lisbon-on-the-rights-of-the-patient/> (accessed 11-08-2019).

her capacity. The legal capacity should be determined and applied as follows: Should the “legally incompetent patient [be able to] make rational decisions”, his or her “decisions must be respected”, and he or she “has the right to forbid the disclosure of information to his [or] her legally entitled representative”. However, if treatment is forbidden by the patient’s legally entitled representative or a person authorised by the patient, but the physician believes it to be in the “best interests of the patient”, then “the physician should challenge this decision in the relevant legal or other institution”. However, in case of an emergency, the Declaration states that “the physician will act in the patient’s best interest”.

4.2.6 Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine

In the 1990s the Council of Europe became concerned about the developments in biomedicine and the possible adverse effects on patients. In particular a threat to human dignity was feared. This Convention constitutes an international instrument aimed at prohibiting the misuse of innovations in biomedicine, thereby endeavouring to protect human dignity in the face of rapidly increasing technological advances. This document was opened for signature on 4 April 1997 in Oviedo, Spain and is thus known as the “Oviedo Convention”. The Convention refers to informed consent in particular.

Article 5 of the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine determines that:

> “An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it. This person shall beforehand be given appropriate information as to the purpose and nature of the

intervention as well as on its consequences and risks. The person concerned may freely withdraw consent at any time."[553]

Article 6 was inserted to protect persons who cannot give free and informed consent in person and reads as follows:

"1 […] an intervention may only be carried out on a person who does not have the capacity to consent, for his or her direct benefit.

3 Where, according to law, an adult does not have the capacity to consent to an intervention because of a mental disability, a disease or for similar reasons, the intervention may only be carried out with the authorisation of his or her representative or an authority or a person or body provided for by law.

The individual concerned shall as far as possible take part in the authorisation procedure.

4 The representative, the authority, the person or the body mentioned in paragraphs 2 and 3 above shall be given, under the same conditions, the information referred to in Article 5.

5 The authorisation referred to [in sub article] 3 above may be withdrawn at any time in the best interests of the person concerned."

Article 9 focusses on previously expressed wishes for example wishes expressed by the patient by means of an advance directive. Article 9 reads as follows:

"The previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account."

[553] Art 5 "Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine" ETS No 164 "Oviedo Convention".

The explanatory report to the Convention clarifies that when previously expressed wishes are “taken into account” as described in article 9, it does not mean that they will necessarily be followed. The example given is of a time-lapse which occurred between the patient expressing his or her wishes and the actual time of the medical intervention. In the interim, science and technology may have progressed to such an extent that the patient’s erstwhile request might no longer have been the same, had he or she been competent to express his or her view at the time of the intervention. In such an instance the explanatory report states that there may be grounds not to heed the patient’s request.

As can be seen from the discussion in 4.2 on international law and international instruments, it is clear that informed consent, medical decision making and reaffirming a patient’s fundamental rights including the rights to life, dignity and access to health care, are investigated on an international level and that international solutions are sought. The legality of living wills and advance directives, as they pertain to specific jurisdictions used in this legal comparative study, will now be investigated. The researcher has selected for purposes of comparison the following countries: the Netherlands, England and Canada. These three countries have different legal frameworks regarding living wills and advance directives and related end-of-life problems. Since the three mentioned countries have all developed their own legal frameworks and guidelines in this field, and since there is currently active debate and continuous legal reform in all three jurisdictions, so as to improve their own end-of-life laws, these countries will make valuable case studies to serve as a point of departure for South African legal development of living wills and advance directives and implementation strategies thereof.

4.3 The Netherlands

4.3.1. Current Legal Position

In the Netherlands living wills and advance directives are legally regulated. The Dutch legal framework caters for different scenarios and possibilities in terms of (1) living wills and (2) advance directives. Each document has its own unique definitions, drafting requirements, characteristics and applicability criteria.

The law in the Netherlands is codified. The specific sections of the Civil Code (*Burgerlijk Wetboek* "BW") concerning advance directives fall under the section law of contracts, specifically law on medical treatment contracts (*De overeenkomst inzake geneeskundige behandeling*) also referred to as the *Wet op Behandelingsovereenkomst* ("WGBO").[554]

Article 446 describes a medical treatment contract as an agreement regarding medical treatment in terms of which, a natural person or legal person, known as the care provider (*hulpverlener*) binds him or herself in the course of his or her medical practice, to another (the *opdrachtgever*) to perform medical treatments or medical actions which directly affect the person who gave the instructions personally (*opdrachtgever*) (*opdrachtgever* as patient) or it may affect a specific third party (third party as patient).[555] The wording of article 446, is as follows:

"1. *De overeenkomst inzake geneeskundige behandeling - in deze afdeling verder aangeduid als de behandelingsovereenkomst - is de overeenkomst waarbij een natuurlijke persoon of een rechtspersoon, de hulpverlener, zich in de uitoefening van een geneeskundig beroep of bedrijf tegenover een ander, de opdrachtgever, verbindt tot het verrichten van handelingen op het gebied van de geneeskunst, rechtstreeks betrekking hebbende op de persoon van de opdrachtgever of van*

[554] *Burgerlijk Wetboek* (BW) *Boek* 7 *Afdeling* 5 "De overeenkomst inzake geneeskundige behandeling" aa 446-468.
[555] Own summary and translation. Original text is provided.

een bepaalde derde. Degene op wiens persoon de handelingen rechtstreeks betrekking hebben wordt verder aangeduid als de patiënt.

2. *Onder handelingen op het gebied van de geneeskunst worden verstaan:*
   a. *alle verrichtingen - het onderzoeken en het geven van raad daaronder begrepen - rechtstreeks betrekking hebbende op een persoon en ertoe strekkende hem van een ziekte te genezen, hem voor het ontstaan van een ziekte te behoeden of zijn gezondheidstoestand te beoordelen, dan wel deze verloskundige bijstand te verlenen;*
   b. *andere dan de onder (a) bedoelde handelingen, rechtstreeks betrekking hebbende op een persoon, die worden verricht door een arts of tandarts in die hoedanigheid.*"[556]

In terms of article 447 when a minor reaches the age of 16 years, he or she is regarded as competent to enter into his or her own medical treatment contracts and to perform legal actions in connection with said medical treatment contracts.[557] Article 447 states that:

"1. *Een minderjarige die de leeftijd van zestien jaren heeft bereikt, is bekwaam tot het aangaan van een behandelingsovereenkomst ten behoeve van zichzelf, alsmede tot het verrichten van rechtshandelingen die met de overeenkomst onmiddellijk verband houden.*

2. *De minderjarige is aansprakelijk voor de daaruit voortvloeiende verbintenissen, onverminderd de verplichting van zijn ouders tot voorziening in de kosten van verzorging en opvoeding.*

3. *In op die behandelingsovereenkomst betrekking hebbende aangelegenheden is de minderjarige bekwaam in en buiten rechte op te treden.*"[558]

Article 450(3) deals with treatment directives and also grants legal force and effect to advance refusals of medical treatment. Article 450(3) states that:

[556] Art 7:446 *Burgerlijk Wetboek* ("BW").
[557] Own summary and translation. Original text is provided.
[558] Art 7: 447 BW.

"*In het geval waarin een patiënt van zestien jaren of ouder niet in staat kan worden geacht tot een redelijke waardering van zijn belangen ter zake, worden door de hulpverlener en een persoon als bedoeld in de leden 2 of 3 van artikel 465, de kennelijke opvattingen van de patiënt, geuit in schriftelijke vorm toen deze tot bedoelde redelijke waardering nog in staat was en inhoudende een weigering van toestemming als bedoeld in lid 1, opgevolgd. De hulpverlener kan hiervan afwijken indien hij daartoe gegronde redenen aanwezig acht*."

In the Netherlands, patients may even provide a written euthanasia directive in their living wills or advance directives to specify the circumstances under which they would require euthanasia for themselves. Euthanasia is however only legal under limited circumstances as determined in the Termination of Life and Assisted Suicide (Review Procedures) Act.[559]

In the following paragraphs living wills (*levenstestamente*) and advance directives (*wilsverklaringe*) are discussed in more detail.

4.3.1.1 The *Levenstestament* (Living Will)

In Dutch law a living will (*levenstestament*) is a document that must be drafted by a notary. Living wills have been described as "een notarieel kroonjuweel, van groot belang voor de sameleving".[560] This document can regulate different aspects of a person's life, not just medical decision making. It may include the appointment of a representative by way of a power of attorney (*volmacht*). Furthermore the living will (*levenstestament*) can also contain a durable power of attorney for medical decisions. The living will thus amounts to a comprehensive power of attorney for the appointment

[559] Termination of Life and Assisted Suicide (Review Procedures) Act (2001). See discussion in para 4.3.3.3 below.
[560] My translation: "A notarial crown jewel: of great importance to society" Van Anken JM, Blankman K, Brinkman RE, van den Broeck A, Denekamp T, Engelbertink CGC, van der Geld LAGM, Heijning SH, Hillen-Muns MIWE, Kortmann SCJJ, Legemaate J, Oomen JH, Schols BMEM, Verstappen LCA *Het levenstestament: Nader verfijnd* (2017) 7.

of one person or different people, to act on behalf of a specific person. The appointee or appointees can thus take decisions on various aspects as stipulated in the living will, including finances, housing and medical matters. The *benoemde vertegenwoordiger* (named representative) in the *levenstestament* can for example be a partner, child or close friend. The *levenstestament* can also contain a request for euthanasia. However, it is not possible for the named representative to request euthanasia on the patient's behalf, as the request must come from the patient personally. The fact that a person has requested euthanasia in a *levenstestament*, however, does not mean that the request will necessarily be granted.[561] The *levenstestament* is legally binding. No doctor may act contrary to its provisions.

4.3.1.1.1 Difference between a Living Will and a Testamentary Will

The living will (*levenstestament*) differs from a testamentary will as the living will concerns instructions regarding future decision making that must be followed while the person who gave the instructions, is still alive. The will (*testament*) concerns the dissolution of a person's estate and the disposal of his or her assets once he or she has passed away. Even though the living wills and testamentary wills must be drafted by a notary in the Netherlands, the two documents are completely different. The *levenstestament* (living will) is for regulating certain aspects, which can include medical aspects, of a person's life while he or she is still alive. On the other hand a *testament* (testamentary will) is for regulating a person's pecuniary interests namely the dissolution of his or her estate and disposal of his or her assets, and the appointment of an executor once he or she has passed away. The two documents are thus applicable to different situations and applicable at different times; the living will during a person's lifetime and the testamentary will, after death. Living wills and testamentary wills thus do not overlap, but they can complement one another.

[561] See discussion in para 4.3.3.3 below.

4.3.1.2 *Wilsverklaringe* (Advance Directives)

It is an option under Dutch law to draft *wilsverklaringe* or *schriftelijke wilsbeschikking* (advance directives). Through the use of an advance directive the maker is given the opportunity to state what he or she would want in terms of end-of-life care, or other care, under given circumstances. With “other care” is meant care that might not yet be end-of-life care, but the type of care that the maker would want for him- or herself when the maker may no longer be mentally competent to give his or her own specific instructions, for example in late-stage dementia.

4.3.1.2.1 Differences between *Levenstestamente* and *Wilsverklaringe*

Wilsverklaringe (advance directives) can be drafted without the assistance of a notary. A notary is allowed to charge professional fees to draft, amend or make any additions to a *levenstestament*. The *Nederlandse Vereniging voor een Vrijwillig Levenseinde* (“NVVE”) provide *wilsverklaringe* free of charge to its members. Since it can be drafted without the assistance of a notary, it can be reviewed and amended free of charge by the maker and thus kept up to date more easily. Since advance directives are personal in nature and tailor-made to specific circumstances, they often carry more weight than *levenstestamente* as far as implementation is concerned. Whereas *levenstestamente* are stored in a registry of *levenstestamente*, advance directives can be held in safekeeping by the makers, copies can be given to nearest and dearest, the makers’ appointed medical proxies and general physicians (“*huisartse”*) to keep on file. The NVVE also keeps a registry of their members’ advance directives.

Different options for advance directives exist, namely *behandelverbod* (do not treat orders), *behandelverbod aanvulling voltooid leven* (do not treat directive completed life), *euthanasieversoek* (euthanasia request), *euthanasieverzoek aanvulling dementie* (euthanasia request in case of dementia) and *volmacht* (medical power of attorney).

The three advance directives that the NVVE provides to its members are discussed below.

4.3.1.2.2 Advance Directives from the NVVE

The NVVE provides three types of *wilsverklaringen* (advance directives) to its members. These comprise the *euthanasieverzoek* (euthanasia request), *behandelverbod* (do not treat order) and the *volmacht* (power of attorney).[562]

1. Euthanasia request (*euthanasieverzoek*)

According to De Vito "The Dutch Law on the termination of life on request and assisted suicide is the oldest euthanasia law (that still exists) in the world.[563] The origins of the term "euthanasia" stem from the classical Greek words "eu" which means "good" and "thanatos" which means "death" in other words "helping somebody to a good death".[564] The act of "euthanasia" is defined in Dutch law as the instance where a doctor kills a person who is suffering "unbearably" and "hopelessly" at the person's explicit request.[565] The act of euthanasia is prohibited by article 293 of the Dutch Penal Code. However, when the act of euthanasia is performed by a medical doctor and under specific conditions, it can be justified and will no longer be regarded as a criminal offence.[566] The "euthanasia request" document states under which circumstances a person requests to be assisted do die. This is however merely a request and the whole process regarding approval for an application for euthanasia, and all the safeguards that go along with it, will have to be followed. The request for euthanasia will thus need to be

[562] NVVE "Wilsverklaringen van de NVVE" <https://www.nvve.nl/onze-diensten/wilsverklaringen-van-de-nvve> (accessed 1-08-2019).
[563] De Vito L "Dutch euthanasia law always meant for groups that now receive euthanasia" Conference World Federation of Right to Die Societies, Cape Town 2018 1 Published in Dutch De Vito L "*Mogelijkheden euthanasiewet zijn niet verruimd*" (September 2018) *Medisch Contact* <https://www.medischcontact.nl/ nieuws/laatste-nieuws/artikel/mogelijkheden-euthanasiewet-zijn-niet-verruimd.htm> (accessed 13-08-2019).
[564] Enschedé Ch J *De Arts en de dood: sterven en recht* (1985).
[565] Griffiths J, Bood A & Weyers H *Euthanasia & Law in the Netherlands* (1998) 17.
[566] See discussion in para 4.3.3.3

approved before euthanasia may be granted. Doctors in the Netherlands require their patients to confirm their requests for euthanasia before the final act, therefore doctors will not merely act on the face of advance instructions contained in an advance directive or living will alone; the request must be confirmed before euthanasia is administered.[567] According to van Delden advance directives which contain written requests for euthanasia are "unfeasible" and it would not be "ethically justifiable to act upon them".[568] He argues that performing euthanasia on incompetent patients on the grounds of a "previously written advance directive is a mistake" as it would create inconsistencies "within the law" and the "moral framework". He also argues that there are ethical problems inherent in advance directives and the "serious lack" of communication between the physician and the patient, if a physician is requested to perform euthanasia in accordance with the request contained in an advance directive for example the requirement that there was no reasonable alternative solution for the situation, would be impossible to meet, in the case of an incompetent patient.[569]

On 11 September 2019 the Den Haag Court delivered a landmark judgment in which it found that a Doctor who had acceded to a severely demented patient's earlier mentally competent request for euthanasia which was documented in a euthanasia declaration, and who could not verify the request before administering the euthanasia medication due to the patient's mental state, did not act unlawfully.[570]

2. No treatment order (*behandelverbod*)

In the *behandelverbod* (no treatment order) the maker can state under which circumstances he or she would not be willing to grant consent to specific treatments.

[567] See Rechtbank Den Haag Zaaknummer 09/837356-18.
[568] van Delden JMM "The unfeasibility of requests for euthanasia in advance directives" (2004) *J Med Ethics* 30 447-452.
[569] van Delden JMM "The unfeasibility of requests for euthanasia in advance directives" (2004) *J Med Ethics* 30 448.
[570] Rechtbank Den Haag Zaaknummer 09/837356-18; BBC News "Dutch euthanasia case: Doctor acted in interest of patient, court rules" (11 September 2019) <https://www.bbc.com/news/world-europe-49660525> (accessed 11-09-2019).

The doctors are then prohibited from performing the medical treatments specified in the *behandelverbod*, since doctors are not allowed to perform medical treatments or procedures without a patient's informed consent.

3. Power of attorney (*volmacht*)

The *volmacht* (power of attorney) document allows the maker to appoint a representative to take medical decisions when he or she is no longer mentally competent to take those decisions. These medical decisions that the representative could take may not include euthanasia, therefore a person who would request euthanasia for him- or herself in future, should draft a specific euthanasia request.[571]

The NVVE provides assistance to its members with the drafting of these advance directive documents. A signed advance directive is a legally binding document. It is therefore not necessary to have an advance directive drafted by a notary, for it to obtain legal status. The NVVE advocates that it is essential for patients to discuss the contents of their advance directives with their treating physicians on a regular basis, so that the treating physicians are aware of their wishes during different stages of illness and life.

4.3.1.3 The Appointment of a Health Care Proxy

In terms of Dutch law a health care representative, called a health care proxy can be appointed to make health care decisions on behalf of a patient when he is she is no longer competent to express his or her health care decisions. There are different types of proxies. A court can appoint a proxy on application, or the patient can appoint his or her own proxy. The court can appoint a curator (to look after a person's estate, financial affairs) or a mentor (to make medical decisions in the case of a patient who is no longer mentally competent to make his or her own decisions). However, it is a much simpler process when the patient appoints someone in a *levenstestament* (living will) or in a

[571] See discussion on proxy directives in para 4.3.3.3 below.

wilsverklaring (advance directive). In all these situations the proxy is then regarded as the legal representative.

In circumstances where a person has not appointed a proxy before he or she becomes mentally incompetent or incapacitated, and where the court has not granted curatorship or mentorship, the Civil Code does provide a mechanism for proxies to be appointed under such circumstances. Relatives are appointed by way of a hierarchal order. Art 465(3) determines that the first appointee will be a spouse or partner, unless it is not what the patient wished. Furthermore, if such spouse or partner is not able to act as a representative or the patient did not wish for them to be appointed, then a parent, child, brother or sister can be appointed, unless the patient did not wish their appointment. No further categories are listed.[572] Article 465(3) of the Civil Code reads as follows:

> "*Indien de meerderjarige patiënt die niet in staat kan worden geacht tot een redelijke waardering van zijn belangen ter zake, niet onder curatele staat of ten behoeve van hem niet het mentorschap is ingesteld, worden de verplichtingen die voor de hulpverlener uit deze afdeling jegens de patiënt voortvloeien, door de hulpverlener nagekomen jegens de persoon die daartoe door de patiënt schriftelijk is gemachtigd in zijn plaats op te treden. Ontbreekt zodanige persoon, of treedt deze niet op, dan worden de verplichtingen nagekomen jegens de echtgenoot of andere levensgezel van de patiënt, tenzij deze persoon dat niet wenst, dan wel, indien ook zodanige persoon ontbreekt, jegens een ouder, kind, broer of zus van de patiënt, tenzij deze persoon dat niet wenst.*"[573]

Therefore, when a patient is no longer in a position to provide medical instructions due to incapacitation or medical incompetence, the appointed medical proxy, either appointed by the patient, the court or through the workings of law, has to decide whether to consent to the treatment or to dispute the treatment and request different treatment.

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[572] Art 7:465(3) BW. Own summary and translation. Original text is provided.
[573] Art 7: 465(3) BW; Leenen HJJ, Dute JCJ, Gevers JKM, Legemaate J, de Groot GRJ, Gelpke ME & de Jong EJC *Handboek Gezondheidsrecht* (2014) 134.

Furthermore, article 465(6) determines that where a patient is against invasive treatment (*een verrichting van ingrijpende aard*), but the legal representative has given consent, the treatment can only be given, if it is necessary to prevent serious harm (*nadeel*) to the patient.[574] Article 456(6) reads as follows:

> "*Verzet de patiënt zich tegen een verrichting van ingrijpende aard waarvoor een persoon als bedoeld in het tweede of derde lid, toestemming heeft gegeven, dan kan de verrichting slechts worden uitgevoerd indien zij kennelijk nodig is ten einde ernstig nadeel voor de patiënt te voorkomen.*"[575]

In terms of article 450(3) the doctor or care provider (*hulpverlener*) can override the legal representative's instructions if there are valid reasons (*gegronde redenen*) to do so. For example, if following the patient's wishes, as directed through the patient's legal representative, would entail that the doctor would have to disregard the standard of care required of a competent care provider, the doctor is legally allowed to override the patient's wishes. Art 450(3) reads as follows:

> "*In het geval waarin een meerderjarige patiënt niet in staat kan worden geacht tot een redelijke waardering van zijn belangen ter zake, worden door de hulpverlener en een persoon als bedoeld in artikel 465, tweede of derde lid, de kennelijke opvattingen van de patiënt, geuit in schriftelijke vorm toen deze tot bedoelde redelijke waardering nog in staat was en inhoudende een weigering van toestemming als bedoeld in het eerste lid, opgevolgd. De hulpverlener* ***kan hiervan afwijken indien hij daartoe gegronde redenen aanwezig acht***".[576]

It is therefore possible that the physician's duty as imposed by the patient himself, or the legal representative, in terms of the *Wet op Behandelingsovereenkomst* can lapse,

[574] Own translation. Original text is provided.
[575] Art 7:465(6) BW; Leenen HJJ, Dute JCJ, Gevers JKM, Legemaate J, de Groot GRJ, Gelpke ME & de Jong EJC Handboek Gezondheidsrecht (2014) 134.
[576] My emphasis. Art 7:450(3) BW; Leenen HJJ, Dute JCJ, Gevers JKM, Legemaate J, de Groot GRJ, Gelpke ME & de Jong EJC Handboek Gezondheidsrecht (2014) fn125 133.

where the decisions or instructions are not reconcilable with "*de zorg van een goed hulpverlener*".[577]

4.3.2 Historical Development: Informed Consent

According to the universal principles of medical ethics, medical personnel must always attempt to first obtain the patient's informed consent. Informed consent can also be given by way of a proxy or advance directive. Under Dutch law, the notion of informed consent is of vital importance in all medical treatment agreements concluded before treatment is initiated. Article 450(1) reads as follows: "*Voor verrichtingen ter uitvoering van een behandelingsovereenkomst is de toestemming van de patiënt vereist*". It is said that "[t]he requirement of informed consent prior to medical intervention is the cornerstone of the Act on Medical Contract and all other laws pertaining to individual life care".[578]

It is also part of the informed consent principle that medical practitioners have the duty to advise patients of all treatment options and the accompanying risks. Article 448 clearly states the medical care provider has to give the patient-specific clear information, which could be in writing if the patient so requests, regarding the planned examination and treatment, as well as any developments relating to the examination, treatment options and information regarding the patient's health status. If the patient is younger than 12 years of age, the health care provider must relay the information in a manner that will be understandable to the patient. The article specifies what information must be relayed to the patient, including the nature and purpose of the examination or treatment, which the care provider regards as necessary. How the examination and treatment will be carried out must also be conveyed. Furthermore, the expected consequences and outcomes of the examination and treatment and the risks it holds to the health of the patient, alternatives to the proposed methods of examination or

[577] Verbogt S & Meersbegen DYA *Hoofdstukken over gezondheidsrecht* (2007) 104-105.
[578] Markenstein LF "Country Report: The Netherlands" 741.

treatment and the state of the patient's health and the prognosis in respect of the examination or treatment, must be communicated.

However, the right to be informed is not unlimited. Dutch law allows for exceptions when it would be permissible for doctors under certain circumstances, to withhold certain information from patients concerning their treatments and the gravity of their medical conditions, and where it is not necessary to obtain consent in emergency situations, the medical actions can be carried out without consent having been granted. The first exception to informed consent is found in article 448(3) which states that the above-mentioned information (as stipulated in article 448(1) and (2)) may be withheld from the patient if providing the information would clearly cause serious harm to the patient.[579] However, if in the interests of the patient, it is required that the information must be given to a person, other than the patient, this must be done. When there is no longer any danger of causing serious harm to the patient, the information must then be provided to the patient. However, the care giver must consult another care giver before information can be withheld from the patient, as described in this section.[580] Article 448 reads as follows:

"1. *De hulpverlener licht de patiënt op duidelijke wijze, en desgevraagd schriftelijk in over het voorgenomen onderzoek en de voorgestelde behandeling en over de ontwikkelingen omtrent het onderzoek, de behandeling en de gezondheidstoestand van de patiënt. De hulpverlener licht een patiënt die de leeftijd van twaalf jaren nog niet heeft bereikt op zodanige wijze in als past bij zijn bevattingsvermogen.*

2. *Bij het uitvoeren van de in lid 1 neergelegde verplichting laat de hulpverlener zich leiden door hetgeen de patiënt redelijkerwijze dient te weten ten aanzien van:*

   a. *de aard en het doel van het onderzoek of de behandeling die hij noodzakelijk acht en van de uit te voeren verrichtingen;*

   b. *de te verwachten gevolgen en risico's daarvan voor de gezondheid van de patiënt;*

[579] Art 7:448(3) BW.
[580] Own summary and translation of art 7:448 BW. Original text is provided.

c. *andere methoden van onderzoek of behandeling die in aanmerking komen;*

d. *de staat van en de vooruitzichten met betrekking tot diens gezondheid voor wat betreft het terrein van het onderzoek of de behandeling.*

4. *De hulpverlener mag de patiënt bedoelde inlichtingen slechts onthouden voor zover het verstrekken ervan kennelijk ernstig nadeel voor de patiënt zou opleveren. Indien het belang van de patiënt dit vereist, dient de hulpverlener de desbetreffende inlichtingen aan een ander dan de patiënt te verstrekken. De inlichtingen worden de patiënt alsnog gegeven, zodra bedoeld nadeel niet meer te duchten is. De hulpverlener maakt geen gebruik van zijn in de eerste volzin bedoelde bevoegdheid dan nadat hij daarover een andere hulpverlener heeft geraadpleegd*."[581]

Article 466 contains another exception to informed consent. Article 466 states that in the case of an emergency in order to perform an action, only the person who must consent in terms of article 465's consent is required, and not the patient's consent. However, if there is not enough time to obtain the article 465 person's consent because immediate action is required to prevent serious harm to the patient, the action may be carried out, without such consent.[582]

The consent that is required, in terms of articles 450 and 465, is presumed to have been given, if the required action is non-invasive. Article 466 reads as follows:

"1. *Is op grond van artikel 465 voor het uitvoeren van een verrichting uitsluitend de toestemming van een daar bedoelde persoon in plaats van die van de patiënt vereist, dan kan tot de verrichting zonder die toestemming worden overgegaan indien de tijd voor het vragen van die toestemming ontbreekt aangezien onverwijlde uitvoering van de verrichting kennelijk nodig is teneinde ernstig nadeel voor de patiënt te voorkomen.*

[581] Art 7:448 BW.
[582] Own summary and translation. Original text is provided.

2. *Een volgens de artikelen 450 en 465 vereiste toestemming mag worden verondersteld te zijn gegeven, indien de desbetreffende verrichting niet van ingrijpende aard is."*[583]

Another exception to informed consent is found in article 449 which states that if the patient has stated that he or she does not wish to receive specific information, such information shall not be provided, on condition that the interest of the patient will be greater than the disadvantages or harm to the patient or to others. Article 449 provides that such information shall not be provided, except where the interest of the patient is outweighed by the harm to himself or to others which may result from withholding the information.[584] Article 449 reads as follows:

> "*Indien de patiënt te kennen heeft gegeven geen inlichtingen te willen ontvangen, blijft het verstrekken daarvan achterwege, behoudens voor zover het belang dat de patiënt daarbij heeft niet opweegt tegen het nadeel dat daaruit voor hemzelf of anderen kan voortvloeien*."

However, should it not be possible to obtain a patient's informed consent from the patient, or from the proxy or the advance directive, then it becomes necessary to reconstruct what the patient would have instructed if he or she had been competent to do so. Moreover, if that is not possible, the best interests of the patient test must be applied.[585] These principles culminate in two models of decision making which are used when a patient is incapacitated and cannot grant informed consent: the "best interests" model and the "substituted judgement" model. The best interests model is a paternalistic model of decision making in terms of which the question is posed: what would be in the patient's best interests. In this scenario what the patient would have

[583] Art 7: 466 BW.
[584] Art 7: 449 BW.
[585] Anderson SJ *Planning for the future: a comparative study of advance directives in Scotland, England and the Netherlands* PhD University of Edinburgh (2004) 128.

wanted, especially if it would have been contrary to his or her best interests, is often ignored.[586]

The "substituted judgement" model of decision making determines that the patient has autonomy and the decision maker must determine what the patient would have chosen. The person's choice of treatment can either coincide with his or her best interests or it can go against it. Anderson explains the difficulty in the implementation of the substituted judgement model as follows:

> "A problem arises when trying to use substituted judgement, as it is never truly possible to know what another person would do in specific situations. This is particularly difficult when the incapacitated person has left no indication of what he or she wished to happen."[587]

4.3.3 Legislative Framework

In summary, the following legislative framework applies to living wills and advance directives:

4.3.3.1 *Wet op Geneeskundige Behandelingsovereenkomst*

As discussed in 4.3.1 the *Wet op de Geneeskundige Behandelingsovereenkomst*[588] ("WGBO") provides that if a person of sixteen years in age or older is no longer mentally competent, a doctor is required to honour a refusal of treatment made in writing when the patient was still competent.[589]

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[586] Anderson SJ *Planning for the future: a comparative study of advance directives in Scotland, England and the Netherlands* PhD University of Edinburgh (2004) 128.
[587] Anderson SJ *Planning for the future: a comparative study of advance directives in Scotland, England and the Netherlands* PhD University of Edinburgh (2004) 128.
[588] Wet op Geneeskundige Behandelingsovereenkomst Burgerlijk Wetboek Boek 7 Afdeling 5 "De overeenkomst inzake geneeskundige behandeling" aa 446-468.
[589] Art 7:450(3) BW.

4.3.3.2 Continuing Powers of Attorney

In the Netherlands continuing powers of attorney are in use. A power of attorney is defined as legal capacity (*bevoegdheid*) granted by a capable adult to another to perform judicial acts on behalf of the granter (om in zijn naam rechtshandelingen te verrichten).[590] The general legislation on powers of attorney applies to this scenario.[591] A continuing power of attorney comes into effect once the granter loses capacity.[592]

4.3.3.3 Termination of Life on Request and Assisted Suicide (Review Procedures) Act

Griffiths states that in terms of Dutch law the act of "euthanasia" is defined as the situation in which a medical doctor kills a person who is suffering "unbearably" and "hopelessly" at the person's explicit request.[593] Article 293 of the Dutch Penal Code reads as follows:

> "1. Any person who terminates another person's life at that person's express and earnest request shall be liable to a term of imprisonment not exceeding twelve years or a fifth category fine.
>
> 2. The act referred to in the first paragraph shall not be an offence if it is committed by a physician who fulfils the due care criteria set out in section 2 of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act, and if the physician notifies the municipal pathologist of this act in accordance with the provisions of section 7, subsection 2 of the Burial and Cremation Act".

The termination of another's life is thus still a criminal offence in the Netherlands. However, the Penal Code creates an exception that if the act is committed by a

[590] Art 3:60 BW.
[591] See Art 3:60 -79 BW.
[592] See 4.3.1.3.
[593] Griffiths J, Bood A & Weyers H *Euthanasia & Law in the Netherlands* (1998) 17.

physician who fulfils the due care criteria set out in section 2 of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act,[594] and if the physician notifies the municipal pathologist of this act in accordance with the provisions of the Burial and Cremation Act (*Wet op lijkbezorging*),[595] he or she does not commit an offence. In the Netherlands euthanasia is generally performed by administering a lethal injection.[596] Since only medical doctors are allowed to perform euthanasia in the Netherlands, in the context of Dutch law, the word euthanasia, typically includes the act of assisted suicide. However, sometimes a distinction is necessary with regard to killing on request (euthanasia) and assisting with suicide (assisted suicide).[597]

In the Netherlands a doctor may in terms of "normal medical practice" provide pain relief in doses likely to cause the death of the patient. In terms of "normal medical practice" a doctor may also either terminate or not initiate life-prolonging treatment that is either medically futile or rejected by the patient. These actions are distinguished from euthanasia, which is regarded as "abnormal medical practice".[598]

In the Netherlands euthanasia was in practice already performed long before the Termination of Life on Request and Assisted Suicide (Review Procedures) Act was enacted in 2002. Two noteworthy cases which sparked law reform, long before the Termination of Life on Request and Assisted Suicide (Review Procedures) Act was enacted, were the *Wertheim* and *Postma* cases. In the *Postma* case the deceased suffered a cerebral haemorrhage, after which she was paralysed on the one side and struggled to communicate verbally. On numerous occasions the deceased asked her daughter, a medical doctor, Dr Postma (the accused), to end her life. She had also told her other daughter and the nursing home staff that she no longer wished to live. Dr Postma eventually administered an injection of morphine to her mother which resulted in her mother's death. The accused's husband, also a medical doctor, was present at

[594] Termination of Life on Request and Assisted Suicide (Review Procedures) Act, 2001.
[595] *Wet op lijkbezorging*,1991.
[596] Griffiths J, Bood A & Weyers H *Euthanasia & Law in the Netherlands* (1998) 17.
[597] Griffiths J, Bood A & Weyers H *Euthanasia & Law in the Netherlands* (1998) 17.
[598] Griffiths J, Bood A & Weyers H *Euthanasia & Law in the Netherlands* (1998) 17.

the time of the lethal injection. As Dr Postma's mother was resident at a nursing home at the time of her death, the director of the nursing home brought the matter to the attention of the Medical Inspectorate. The accused was subsequently charged under article 293 of the Penal Code for "killing on request".

The Medical Inspector testified that times were changing in the Netherlands and that "the average doctor in the Netherlands no longer considered it necessary to prolong a patient's life endlessly". In his opinion it was widely accepted in the medical fraternity that when a patient is given pain relief, and dies more quickly because of the pain relief treatment, than would have been the case had it not been given, under certain conditions, the pain relief treatment could be accepted. The conditions listed for such a practice to be accepted were: the patient must be incurably ill, the patient must find his or her suffering mentally and physically unbearable, the patient must have expressed the wish to die, the patient must be in the terminal phase of his illness, the person who accedes to the request must be a doctor, and preferably the doctor himself or herself must be responsible for the treatment.[599]

The District Court largely agreed with the Medical Inspector's conditions, but found that the condition relating to the terminal phase of illness was not acceptable. The Court said that it knew of "many cases of incurable illness or accident-caused disability, combined with serious physical and/or mental suffering, where the patient was otherwise healthy and could continue living in such a state for years. It was not the court's view that such suffering should be denied the relief described by the expert witness [Medical Inspector]".[600]

The court looked closely at the intention of the accused. On the facts, the court found that Dr Postma's primary intention was in fact to cause the death of her mother by

[599] *Nederlandse Jurisprudentie* 1973, no 183:558 in Griffiths J, Bood A & Weyers H *Euthanasia & Law in the Netherlands* (1998) 52.
[600] *Nederlandse Jurisprudentie* 1973, no 183:560 in Griffiths J, Bood A & Weyers H *Euthanasia & Law in the Netherlands* (1998) 52.

administering an injection that had instantaneous lethal effect. The court found her guilty of murder but gave her a light sentence amounting to one week suspended sentence and one year's probation. According to Griffiths, although the court did not specifically mention this point, it does seem that the ruling was based on the difference between indirect euthanasia, which the Medical Inspector referred to and direct euthanasia, which Dr Postma performed.[601] This case reminds one of the South African *S v Hartmann*[602] case in which Dr Hartmann helped his very ill father to die and was also given a light sentence.[603]

According to Griffiths *et al,* the *Postma* case gained a lot of media attention and mobilised pro-euthanasia groups, such as the NVVE that was established in 1973, as well as opponents of euthanasia. Griffiths said that there were several other cases of people "killing on request" where they were also prosecuted for violating articles 293 and 294 of the Penal Code, but for which they received light sentences.[604]

In the *Wertheim* case Ms Wertheim, a 76-year-old woman, was arrested for helping a 67-year old woman who suffered from physical and mental ailments and who on many occasions expressed her wish to die, to commit suicide. Her *huisarts* had refused to help her, but had put her in contact with Ms Wertheim. Ms Wertheim mixed approximately 30 vesparax tablets in a bowl of custard and fed it to the woman followed by an alcoholic drink to enhance the effects of the medication. The woman died shortly thereafter. The prosecution argued that this was a case of murder, but Wertheim's attorney argued that only assistance with suicide was proven. The District Court agreed with Wertheim's lawyer's submission. The District Court conceded that the assistance of others in committing suicide is sometimes indispensable, but since it is prohibited in terms of article 294, it can only justified if specific requirements are met, namely that the physical and mental suffering of the person must be unbearable to him or her; the

[601] Griffiths J, Bood A & Weyers H *Euthanasia & Law in the Netherlands* (1998) fn29 52.
[602] *S v Hartmann* 1975(3) SA 532 (C).
[603] See discussion of *S v Hartmann* 1975(3) SA 532 (C) in Chapter 5 para 5.10.5.2.
[604] Griffiths J, Bood A & Weyers H *Euthanasia & Law in the Netherlands* (1998) 53.

suffering and the desire to die must be enduring, the person's decision to die must have been made on a voluntary basis, the person had to be well informed regarding his or her situation and the available alternatives, had to be able to weigh the relevant considerations and have done so on the facts, there must also not have been any alternative means to improve the patient's suffering and the person's death should not have caused others unnecessary suffering.[605] The court furthermore said that the assistance itself had to meet certain requirements, namely that the decision to give assistance may not have been made by one person alone, a doctor must have been involved in both the decision whether to give assistance and the determination of the method to be used. Furthermore the decision to give assistance and the assistance itself had to be given with the utmost care which entailed that the matter had to be discussed with other doctors if the patient's condition was in the terminal phase, and if the patient had not yet reached the terminal phase, other experts needed to be consulted such as psychiatrists, psychologists or social workers. On the facts, the District Court held that Ms Wertheim did not meet these requirements and found her guilty of assisting in suicide. The court found that a jail sentence would have been too much of a mental and physical burden given her age and therefore gave her a conditional sentence of six months which was subject to one year's probation. She was placed under house arrest for the first two weeks of probation. The *Wertheim* case was instrumental in the National Committee of Prosecutors General deciding that every case of euthanasia (article 293) or assistance in suicide (article 294) was to be referred to the Committee of Prosecutors General on a decision whether to prosecute or not. The *Postma* and *Wertheim* cases served as guidelines.

The *Schoonheim* decision was the first Supreme Court euthanasia case of a *huisarts* who had performed euthanasia on a 95 year old patient who had requested him to do so on several occasions and in a serious manner.[606] The patient had been bed-ridden due to a hip fracture with eyesight and hearing deteriorating, but she was mentally fully aware and found her situation humiliating. Before administering the medicine,

[605] Griffiths J, Bood A & Weyers H *Euthanasia & Law in the Netherlands* (1998) 59.
[606] Enthoven 1988: 95 in Griffiths J, Bood A & Weyers H *Euthanasia & Law in the Netherlands* (1998) 62.

Schoonheim spoke to the patient in the presence of family members and her assistant to whom she confirmed that she wanted to die as soon as possible. Schoonheim then injected her with a drug to make her partly lose consciousness and a muscle relaxant to cause her death. Schoonheim reported his actions to the police on the same day. Schoonheim's lawyer argued two defences, the first being that there had been an absence of substantial violation of the law and the second being *overmacht* (necessity). After a legal battle the case reached the Supreme Court.[607] The Supreme Court upheld the finding of the Court of Appeal, Amsterdam namely that "the doctrine of absence of substantial violation of the law" could not be relied on as a defence. The Supreme Court however found that the defence of *overmacht* had not been properly considered by the Court of Appeal and referred the case to the Court of Appeal in the Hague. The Court of Appeal, the Hague, ruled that Schoonheim's defence of necessity was well-founded and he was subsequently acquitted.[608] This was the first time that a doctor who had performed euthanasia was not held criminally liable.[609]

The next case to reach the Supreme Court was the *Pols* case. The facts are as follows. Ms Pols, a psychiatrist killed her friend, a 73 year old suffering from multiple sclerosis, at her friend's request. Ms Pols gave her friend a fast-working tranquiliser and a glass of port. After a few hours she injected her three times with morphine which led to her demise. On that same night she delivered letters to her friend's *huisarts* and the prosecutor, informing them of her conduct and she also informed the institution where the friend had been resident of her deed. Ms Pols' lawyer argued that two defences, namely "absence of substantial violations of the law" and *overmacht*, were applicable. The District Court rejected the first defence but held that a medical exception of *overmacht* had in theory been available but rejected on the facts, because Ms Pols had failed to consult another doctor. Therefore the court found that neither necessity nor duress had been proved, and found Ms Pols guilty, but the court did not impose a

[607] *Nederlandse Jurisprudentie* 1983, no 407; 1984, no 43; 1985, no 106.
[608] *Nederlandse Jurisprudentie* 1987, no 608 in Griffiths J, Bood A & Weyers H *Euthanasia & Law in the Netherlands* (1998) 63.
[609] Griffiths J, Bood A & Weyers H *Euthanasia & Law in the Netherlands* (1998) 63.

sentence. The Court of Appeal, Leeuwarden rejected both defences and found her guilty and imposed a conditional jail sentence of two months subject to two months' probation. On appeal, the Supreme Court held that the notion of a medical exception was rejected. The Supreme Court held that the euthanasia prohibition in article 293 was not intended as subject to an exception for doctors. The court furthermore held that there was no settled consensus that euthanasia amounts to what is known as "normal medical practice" that could be classed as a medical exception. The Supreme Court disagreed with the Court of Appeal's rejection of the defence of *overmacht* (in the form of necessity).[610] The Supreme Court thereafter referred the case to the Court of Appeal, Arnhem. The court of Appeal, Arnhem rejected the defence of *overmacht* in necessity and stated that Ms Pols should have discussed the matter with colleagues because she inter alia had a friendship relationship with the deceased. On a second Appeal to the Supreme Court, the Supreme Court upheld the decisions of the Court of Appeal, Arnhem.

After the *Schoonheim* and *Pols* cases, there was more legal certainty with regard to defences that could be raised to assert the legality of euthanasia. In summary, the Supreme Court rejected the defences of "medical exception" and "absence of substantial violation of the law". However, the Supreme Court held that a doctor could raise the defence of *overmacht* to justify necessity based on a conflict of duties.

The Dutch Medical Association (KNMG) published a report on the requirements of careful practice. The Board found that euthanasia was an issue to be solved within the doctor-patient relationship. The Board then came to the conclusion that if a doctor has taken adequate steps to meet the five requirements of careful practice, the euthanasia performed by him or her, would be acceptable. The five requirements were: the euthanasia request had to be voluntary; the request had to be well considered, the patient must have had a lasting desire to die, the patient's suffering must be

[610] *Nederlandse Jurisprudentie* 1987, no 607 in Griffiths J, Bood A & Weyers H *Euthanasia & Law in the Netherlands* (1998) 64.

unacceptable to him and that the doctor is under an obligation to consult a colleague.[611] Later the requirement of a fully documented record was added as the sixth requirement.[612] In the *Admiraal*[613] case, which concerned an anaesthetist who ended a multiple sclerosis patient's life on request, the District Court found that a doctor who complies with the requirements of careful practice, cannot be convicted for performing euthanasia. Thereafter more legal development took place when the *Chabot* case was heard. In the *Chabot* case the court found that a patient's suffering need not be physical and terminal, but can be non-somatic.[614]

In the *Chabot* case the deceased was a 50 year - old woman who had married and had two sons. Her eldest son had committed suicide at the age of 20, in 1986 while he was serving military duty in Germany. The deceased then indicated that she only wanted to live as long as her second son was still alive. Her father died, she got divorced and her second son died of cancer at the age of twenty, in May 1991. The deceased tried to commit suicide the night of her second son's passing by taking medication prescribed by her psychiatrist, which she had stockpiled. The suicide attempt was unsuccessful and she again started stockpiling medication. She discussed suicide methods with others and contacted a psychiatrist, Chabot, at the Dutch Voluntary Euthanasia Society. Chabot had four sessions with the deceased totalling between 24 and 30 hours, during which the deceased's sister and brother-in-law were also present from time to time. Chabot diagnosed the deceased as suffering from a depressive disorder without signs of psychosis and found that she was still struggling through a process of mourning. Chabot wrote a case summary and requested experts' opinions. The majority of the experts agreed that Chabot should assist the deceased. Chabot was unsuccessful in dissuading the deceased to change her mind or postpone her decision, and agreed to

[611] KNMG 1984:993 in Griffiths J, Bood A & Weyers H *Euthanasia & Law in the Netherlands* (1998) 66.
[612] KNMG 1992:30 in Griffiths J, Bood A & Weyers H *Euthanasia & Law in the Netherlands* (1998) fn76 66.
[613] *Nederlandse Jurisprudentie* 1985, no 709 in Griffiths J, Bood A & Weyers H *Euthanasia & Law in the Netherlands* (1998) 66-67.
[614] See discussion on the *Chabot* case in Malherbe R and Venter R "Die reg op lewe, die waarde van menslike lewe en die eutanasie-vraagstuk" (2011) 3 *TSAR* 487-488.

help the deceased to commit suicide by obtaining the required pills. On 28 September 1991, in the presence of Chabot, a house doctor and a friend, the deceased took Chabot's prescribed lethal drugs and passed away. Afterwards Chabot reported the unnatural death as prescribed. He was subsequently charged of contravening article 294 of the Dutch Criminal Code. The Assen court acquitted Chabot. The Ministry of Justice appealed to the Dutch Supreme Court. According to Griffiths, the Dutch Supreme Court found that in a case where a patient is suffering from a somatic illness and is not in a terminal phase of illness, assistance with suicide can be legally justifiable. The court held that a person who is suffering from a psychiatric illness or disorder has a right to die, which can legally be considered the result of an autonomous judgement if it was a competent and voluntary decision by the patient. The court held that in principle a person cannot be found to be "lacking any prospect for improvement" if he or she has refused a realistic (therapeutic) alternative. The court determined that in this case it was a legal requirement for the defence of necessity to succeed, that an independent colleague must have examined the patient. Chabot had failed to consult an independent psychiatric consultant to examine the deceased, and was subsequently found guilty. According to Griffiths "…the court expressed the belief that such consultation was necessary in the absence of physical illness" but "because it felt that in all other regards Chabot had behaved responsibly", it did not impose punishment.

Further legal development and research into draft legislation took place which led to the enactment of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act.[615] The Termination of Life on Request and Assisted Suicide (Review Procedures) Act states the conditions which govern euthanasia. The Act states that requests for euthanasia (ending a life on request) is an extreme measure in cases where there is no hope of recovery and suffering cannot be cured in any other way.

[615] For a historical overview of events leading up the enactment of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act, 2001 see South African Law Commission, Discussion Paper 71, *Report Project 86 Euthanasia and the Artificial Preservation of Life* (1997) 70-74; Grové LB *Framework for the implementation of euthanasia in South Africa* (2007) (LLM Dissertation University of Pretoria) 128-131. See Griffiths J, Bood A & Weyers H *Euthanasia & Law in the Netherlands* (1998) 68-90.

Under the Termination of Life on request and Assisted Suicide Act[616] an Advance Directive may be applied when the patient "is no longer able to express his will".[617] If a patient is still mentally competent during his or her illness and he or she is still able to convey his or her own medical instructions and wishes, these wishes as verbally communicated, will be relied upon and any advance directive *(wilsverklaring*) or living will (*levenstestament*) will be irrelevant. However, when a patient is in a situation with no hope of recovery (*uitzichtloze toestand*) and mentally incompetent or incapacitated, then the advance directive (*wilsverklaring*) and living will (*levenstestament*) documentation become very important. In brief the requirements for a euthanasia directive are the following: the directive must be in the patient's own handwriting and at least two physicians, the second being independent from the first physician, have to agree that the patient is terminally ill and that no hope for recovery exists.

Wilsbekwaamheid (mental competence) is a prerequisite for a voluntary and well-considered request (making it a valid request) for euthanasia, assisted suicide or for a valid refusal of medical treatment.

The Dutch law therefore does not grant a patient a right to euthanasia per se. Doctors who have principled objections to perform euthanasia and who do not wish to assist with euthanasia and assisted suicide are not obliged to do so. Doctors who have principled objections against euthanasia as well as assisted suicide, should be respected. The treating physician should timeously and clearly talk to the patient about options. During such a discussion the doctor should timeously and clearly express his own view of euthanasia and assisted suicide, so that the patient is informed of the doctor's view in this regard.

According to Griffiths *et al*, referring to the legal position in the Netherlands, people should be allowed to decide for themselves the moment and manner of their own deaths and the law should provide scope for people to make these decisions. Griffiths

[616] Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001.
[617] Art 2(2)Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001.

states that it is imperative that more effective legal control must be exercised to prevent the abuse of the power unavoidably involved in medical care which results in death, but emphasises that effective legal control is not more necessary for euthanasia than it is in other related types of medical interventions that shorten life.[618]

The Dutch Medical Council (KNMG) has published widely on end-of-life issues and has provided parameters and procedures for doctors who are willing to perform euthanasia and assisted suicide. These guidelines are periodically updated. In its project *'Euthanasie bij dementie'* the KNMG for example researched under which conditions it would be professionally accountable to perform euthanasia with reference to people at different stages of dementia.[619]

The Dutch legal system distinguishes another category of actions which is closely related to euthanasia, namely the administration of lethal medicines to shorten the life of persons who cannot and do not explicitly request their lives to be shortened in that manner.[620] These persons who are unable to explicitly request that their lives be shortened by the use of lethal medicines, include people in long term coma's, severely defective new born babies, persons in the final stages of dying and persons who are no longer competent who at an earlier time indicated a general wish for euthanasia if the time should arise.[621] All such euthanasia, assisted suicide and controversial medical practices when initiated by doctors are classed as "medical behaviour that shortens life" (MBSL).[622] According to Griffiths et al the law surrounding MBSL is clear, except as far as advance directives requesting euthanasia in the case of dementia patients and patients who are suffering non-somatically are concerned.[623]

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[618] Griffiths J, Bood A & Weyers H *Euthanasia & Law in the Netherlands* (1998) 16.
[619] KNMG "Euthanasie"< https://www.knmg.nl/advies-richtlijnen/dossiers/euthanasie.htm> (accessed 25-06-2019).
[620] Griffiths J, Bood A & Weyers H *Euthanasia & Law in the Netherlands* (1998) 18.
[621] Griffiths J, Bood A & Weyers H *Euthanasia & Law in the Netherlands* (1998) 18.
[622] Griffiths J, Bood A & Weyers H *Euthanasia & Law in the Netherlands* (1998) 18.
[623] Griffiths J, Bood A & Weyers H *Euthanasia & Law in the Netherlands* (1998) 154.

It is also possible in the Dutch system to assist psychiatric patients and others who are suffering non-somatically with suicide, as discussed above in the *Chabot* case. In the *Brongersma* case the accused, a medical doctor, assisted with the suicide of a man who was 86 years old and felt that his life had become meaningless and too much of a burden and therefore wanted assistance to die. This request is known in literature as a so-called "completed life" request for euthanasia.[624] The court had to determine whether the test for unbearable and hopeless suffering was subjective or objective, in other words whether it was solely up to the patient to decide whether his suffering was unbearable and hopeless, or if it had to be determined objectively. The Haarlem District Court interpreted the requirement of unbearable suffering very broadly and acquitted the doctor. The Amsterdam appeal court found the medical doctor guilty of assisted suicide, but recognised that he acted out of concern for his patient and therefore the court did not impose punishment. The medical doctor tried to appeal his conviction but the Supreme Court dismissed his appeal. The *Brongersma* case is taken as precedent that a person cannot request euthanasia or assisted suicide because of that person's subjective consideration that his or her life is complete.[625]

If a patient wants to request euthanasia, the patient has to sign a written request for euthanasia which the doctor has to keep on file. Hospitals must have draft Euthanasia Directives at their disposal. It is possible to refer to a *wilsverklaring inzake euthanasie* (euthanasia declaration) in a *levenstestament* (living will). In the *wilsverklaring inzake euthanasie* the maker requests his or her doctor to perform euthanasia on him or her should it be legally permissible under the circumstances. A patient cannot compel a specific doctor to perform euthanasia on him or her. The law compels the doctor, when

[624] De Vito L "Dutch euthanasia law always meant for groups that now receive euthanasia" Conference World Federation of Right to Die Societies, Cape Town 2018 4-6 Published in Dutch De Vito L "*Mogelijkheden euthanasiewet zijn niet verruimd*" (September 2018) *Medisch Contact* <https://www.medischcontact.nl/nieuws/laatste-nieuws/artikel/mogelijkheden-euthanasiewet-zijn-niet-verruimd.htm> (accessed 13-08-2019).

[625] De Vito L "Dutch euthanasia law always meant for groups that now receive euthanasia" Conference World Federation of Right to Die Societies, Cape Town 2018 4-6 Published in Dutch De Vito L "*Mogelijkheden euthanasiewet zijn niet verruimd*" (September 2018) *Medisch Contact* <https://www.medischcontact.nl/ nieuws/laatste-nieuws/artikel/mogelijkheden-euthanasiewet-zijn-niet-verruimd.htm> (accessed 13-08-2019).

a euthanasia request is made, and he or she does not wish to perform the euthanasia, to refer the patient to another doctor who might be willing.

The Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001) provides that certain due care criteria must apply to written declarations[626]. These due care criteria include that the substantive requirements of "voluntariness" and "careful consideration" of the request must also be applicable.

Because Dutch legislation does not provide a person with a right to euthanasia, but only with a right to request euthanasia, it is of utmost importance that there should be a relationship of trust between the patient and the treating physician. The due care criteria include that the attending physician must be satisfied that the patient has made a voluntary and carefully considered request and that the patient's suffering is unbearable, before he or she can be successful in the request for euthanasia. Furthermore, the attending physician must be satisfied that there are no prospects of improvement in the patient's condition; that he as the physician has informed the patient about his situation and has come to the conclusion, together with the patient, that there is no reasonable alternative but euthanasia in the light of the patient's situation. The attending physician must also have consulted at least one other independent physician, who must have seen the patient and given a written opinion on the due care criteria above.[627]

In so far as terminology is concerned in the Dutch law "euthanasia" refers to the situation in which the physician (only a physician is allowed to perform this act) kills a person who is suffering unbearably and hopelessly at the person's explicit request. This usually entails the physician administering a lethal injection. Therefore the concept of euthanasia includes the concept of assisted suicide. It is however sometimes necessary

[626] Due care criteria as found *mutatis mutandis* in s 2.1. Termination of Life on Request and Assisted Suicide (Review Procedures) Act, 2001.
[627] According to s 2.1. e Termination of Life on Request and Assisted Suicide (Review Procedures) Act, 2001.

to draw a distinction between euthanasia and other types of assistance with suicide, but generally the term euthanasia can be used to describe the act of euthanasia and of assisted suicide.[628]

Article 2 of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act[629] reads as follows:

In order to comply with the due care criteria referred to in section 293, paragraph 2, of the Criminal Code[630], the attending physician must

(a) be satisfied that the patient has made a voluntary and carefully considered request;

(b) be satisfied that the patient's suffering was unbearable, and that there was no prospect of improvement;

(c) have informed the patient about his situation and his prospects;

(d) have come to the conclusion, together with the patient, that there is no reasonable alternative in the light of the patient's situation;

(e) have consulted at least one other, independent physician, who must have seen the patient and given a written opinion on the due care criteria referred to in (a) to (d) above; and

(f) have terminated the patient's life or provided assistance with suicide with due medical care and attention.[631]

These legal requirements have to be supplemented by the requirements of careful practice that are derived from self-regulation.[632] The physician has to discuss the matter

[628] Griffiths J, Bood A & Weyers H *Euthanasia & Law in the Netherlands* (1998) 17.
[629] Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001.
[630] S 293(2)Criminal Code RSC 1985 c C-46.
[631] Translation used by UK Parliament Select Committee on Assisted Dying for the Terminally Ill Bill "Termination of Life on Request and Assisted Suicide (Review Procedures) Act <https://publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/4121603.htm> (accessed 2019-08-02). See alternative English translation De Haan, J "The New Dutch Law on Euthanasia" (Spring 2002) Medical Law Review 10 68-69.
[632] H Nys "Euthanasia in the Low Countries: A comparative analysis of the law regarding euthanasia in Belgium and the Netherlands" 10.

with the immediate family and or close friends (unless the patient does not want this or there are other good reasons for not doing so) and with nursing personnel responsible for the patient's care. He also has to keep a full written record of the case (including information concerning the other elements of careful practice).

The Termination of Life on Request and Assisted Suicide (Review Procedures) Act provides further that the termination of another person's life at that person's request is not an offence, if the due care criteria described above are met and if the physician notifies the municipal pathologist of his act in accordance with the provisions of the Burial and Cremation Act.[633] The Burial and Cremation Act[634] determines that if death is the result of euthanasia, the attending physician shall not issue a death certificate and shall immediately notify the municipal pathologist of the cause of death by completing a report form.[635] Together with the report form, the attending physician also has to provide a detailed report on compliance with the due care criteria of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act.

The Burial and Cremation Act obliges the municipal pathologist to report to the competent regional review committee referred to in section 3 of the Termination of Life on Request and Assisted Suicide Act, without any delay.[636] The regional review committee will make an assessment based on the pathologist's report and make a finding on whether the physician has acted in accordance with the due care criteria. The committee may also obtain information from the municipal pathologist, the independent physician or the relevant health care providers, if this is necessary for a proper assessment of the attending physician's conduct.[637] If the committee is of the opinion that the attending physician did not act in accordance with the due care principles, certain bodies need to be informed of their findings, namely the Board of Prosecutors

[633] S 7.2 Burial and Cremation Act 1991 (*Wet op de Lijkbezorging* 1991).
[634] Burial and Cremation Act 1991.
[635] S 7.2 Burial and Cremation Act 1991.
[636] S 10 Burial and Cremation Act 1991.
[637] S 8 Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001.

General of the Public Prosecution service and the regional health inspector.[638] The regional review committee is obliged to provide the public prosecutor with all the information that he may require to assess the physician's conduct and for the purpose of a criminal investigation.[639]

The *Heringa* case received a lot of media attention. This case dealt with the situation where the person who assisted with the death was not a medical physician. In the Albert Heringa case the accused, Heringa, assisted his elderly mother of 99 years to die. Doctors had earlier refused her request for euthanasia. He therefore decided to assist her. He also filmed the whole process of assisting his mother to take the medication that caused her death. She had gathered and stored the medication on her own. His mother had been nearly blind and had been suffering excruciating back pain. The film footage was broadcast in a documentary called *De laatste wens van Moek.*[640]

A lengthy court battle ensued. On appeal, the Supreme Court originally cleared Heringa of all charges, but in March 2017 the Supreme Court stated that there should be a re-trial, for the reason that if euthanasia is performed by someone, other than a doctor, it must be subjected to very strict rules. In the subsequent re-trial Heringa's six month suspended jail sentence, which he had appealed earlier, was upheld.

4.3.4 Drafting, Validity, Applicability and Safekeeping of Living Wills and Advance Directives

As far as drafting of advance directives is concerned, the Dutch law does not contain any formal requirements or specific conditions, except that the advance directive has to be made in writing, and the patient's name, date and signature have to be present.[641] It is important to note that the *wilsverklaring* (advance directive) must have been drafted

[638] Section 9(2) Burial and Cremation Act 1991.
[639] Section 10 Burial and Cremation Act 1991.
[640] Translation: Mom's final wish.
[641] Markenstein LF "Country Report The Netherlands" in Taupitz J *Regulations of Civil Law to Safeguard the Autonomy of Patients at the End of Their Life – An International Documentation* 747.

when the patient was still mentally competent. In principle the patient can draft the declaration him- or herself, such as by utilising the advance directive templates of advance directives (wilsverklaringen) provided by the NVVE to its members, namely *euthanasieverzoek* (euthanasia request), *behandelverbod* (do not treat order) and the *volmacht* (power of attorney).[642]

Levenstestamente however need to be drafted by a notary. As discussed in paragraph 4.3.1.1 above, the *levenstestament* document can regulate different aspects of a person's life, not just medical decision making, but also finances and other aspects, therefore the knowledge of a legal expert is required. Nys comments that the actual practice of euthanasia in terms of an advance directive is so exceptional that no further formal requirements or conditions are to be found in jurisprudence or in self-regulation.[643] A euthanasia directive is thus not of great value if the person is found to be mentally incompetent and unable to confirm his or her request.

In so far as the safekeeping of living wills is concerned, all *levenstestamente* in the Netherlands are stored on a special register of *levenstestamente* for easy access. The NVVE has a database on which all their members' advance directives are stored. The Dutch public health care system is unique that each Dutch inhabitant is appointed and registered with a general physician known as a *huisarts*. According to Griffiths, Bood and Weyers these general physicians fulfil three functions, namely "listing", "gatekeeping" and "family orientation".[644] "Listing" means that each Dutch inhabitant is registered with a *huisarts*, "gatekeeping" in terms of which a patient does not generally have direct access to specialists or hospital care, but has to work through their *huisarts*, and the third function is "family orientation" in terms of which a *huisarts* is generally the medical practitioner for the patient's whole family. It is recommended that the maker of

[642] NVVE "Wilsverklaringen van de NVVE" <https://www.nvve.nl/onze-diensten/wilsverklaringen-van-de-nvve> (accessed 1-08-2019).
[643] Nys H "Euthanasia in the Low Countries: A comparative analysis of the law regarding euthanasia in Belgium and the Netherlands" Centre for Biomedical Ethics and Law, Faculty of Medicine, K.U. Leuven & Maastricht University 7. See van Delden JMM "The unfeasibility of requests for euthanasia in advance directives" (2004) *J Med Ethics* 30 447-452.
[644] Griffiths J, Bood A & Weyers H *Euthanasia & Law in the Netherlands* (1998) 37.

any advance directives should provide a copy to his or her nearest family and friends and to his or her *huisarts*. In so doing the advance directive will become part of his or her medical record. The appointed medical proxy should of course also have a copy on hand to prove his or her appointment as a proxy, and to enable the proxy to act timeously.

In summary, in the Dutch legal system and medical practice there already exists a legal framework and practice which govern the making and execution of end-of-life decisions including living wills and advance directives.[645] In the next paragraphs, the researcher will focus on the second country which was elected for discussion, namely England, where a different legal dispensation exists with reference to advance decisions.

4.4 England

4.4.1 Current Legal Position

In terms of the English common law advance decisions (also known as advance refusals of health care or living wills) were recognised as valid and enforceable.[646] In the English law the terms "advance decision", "advance refusal of medical care" and "living wills" are in fact used interchangeably. The terminology with reference to living wills and advance directives, as well as the execution of these documents, thus existed prior to the Mental Capacity Act,[647] which came into operation in 2007, and which is applicable in England and Wales. The Mental Capacity Act becomes relevant once a person starts to lack mental capacity. It is therefore imperative that any advance decisions (living wills) that were drawn up before the Mental Capacity Act came into operation should be revised as they may not meet all the requirements as stipulated in the Act.

[645] See Chapter 6 para 6.2.5.1.1 where the relevance of Dutch law to law reform in South African in the context of living wills and advance directives, is discussed.
[646] Jordaan L "The legal validity of an advance refusal of medical treatment in South African law (Part 2) (2011) *De Jure* 266.
[647] Mental Capacity Act, 2005.

4.4.2 Historical Development: Informed Consent

It is a principle of English medical law that a competent adult patient must provide consent to medical treatment.[648] The consent has to be in line with specific criteria to convert what could have been an unlawful act, to lawful conduct. The specific elements are the following: the patient must have the capacity to consent, the consent must have been given voluntarily and the patient must have understood the nature of the treatment that was consented to. In *Airedale NHS Trust v Bland*[649] the House of Lords found that an adult patient with capacity has the right to refuse medical treatment, even if the refusal is not in his or her best interests. The Court of Appeal in *Re T (Adult: Refusal of Treatment)*[650] stated that an adult's "right of choice [with reference to medical treatment] is not limited to decisions which others might regard as sensible. It exists notwithstanding that the reasons for making the choice are rational, irrational, unknown or even non-existent".[651] Where a person lacks capacity to consent the legal provisions of the Mental Capacity Act[652] must be followed.

4.4.3 Legislative framework

4.4.3.1 Mental Capacity Act

In England the living will for medical treatments is governed by the Mental Capacity Act.[653] The Mental Capacity Act defines an "advance decision" as follows:

> "(1) a decision made by a person ("P"), after he has **reached 18** and when he has **capacity** to do so, that if—

[648] See Herring J *Medical law and ethics* (2008) 156-157 for list of exceptions where consent is not a necessary requirement before treatment can take place.
[649] *Airedale NHS v Bland* [1993] AC 789.
[650] *Re T (Adult: Refusal of Treatment)* [1993] *Fam* 95.
[651] Lord Donaldson MR in *Re T (Adult: Refusal of Treatment)* [1993] Fam 95.
[652] Mental Capacity Act, 2005.
[653] Mental Capacity Act, 2005 and supplemented by Statutory Instrument 2007 No 253 on lasting powers of attorney, enduring powers of attorney and public guardian regulations.

(a) at a later time and in such circumstances as he may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for him, and
(b) at that time he **lacks capacity to consent** to the carrying out or continuation of the **treatment**, the specified treatment is **not** to be **carried out or continued**.

(2) For the purposes of subsection (1)(a), a decision may be regarded as specifying a treatment or circumstances even though expressed in **layman's terms**".[654]

It is clear from the wording of the Mental Capacity Act above, that "advance decisions" therefore amount to advance refusals of medical treatment and can only be used by an individual to convey instructions to refuse any medical treatment including life-sustaining treatment, such as cardiopulmonary resuscitation. The advance decision must be made by a competent person with the required mental capacity. The competent person must be over the age of 18 years.

Capacity is thus a fundamental aspect to the making an advance decision. Capacity can be defined as a patient's ability to make a decision for him- or herself. It's time-specific and decision-specific. The inquiry into whether or not the patient is able to make a decision depends on when the decision needs to be made and what the specific decision entails. It is therefore possible that the patient lacks capacity to make certain decisions on a specific day but not on another, as could be the case if the patient suffers from a condition such as dementia. The complexity and seriousness of the decisions also depend on a patient's capacity. Patients might have the legal capacity to make certain simple decisions, for example what they would like to eat and might not have legal capacity to make other more serious decisions, for example whether life-sustaining treatment should be prolonged. Capacity is judged on whether the patient

[654] My emphasis. Ss 1 & 2 Mental Capacity Act, 2005.

has an impairment or disturbance of the mind or brain (for example in cases of unconsciousness, dementia, other mental health conditions, brain injury or a stroke) and if such impairment causes the patient to not understand information relating to the decision, or retain that information for long enough to make the decision or to take that information into account when making the decision, or to communicate the decision.

The law in England holds that people must be assumed to have capacity unless it is proven otherwise. The Mental Capacity Act Code of Practice states it clearly that there is an assumption that the person who made the advance decision did have capacity when he or she made the advance decision.

If a health care professional has reason to doubt a person's capacity, then he or she will need to assess whether the person is able to make the decision in question. In *A Local Authority v E*[655] case, E had attempted to execute an advance decision refusing force feeding despite her psychiatrist's view that she had capacity at the time, Peter Jackson J held that she did not, and hence it was not a binding advance directive for the purposes of the Act. In E's case, given her long history of anorexia, the presumption of capacity appeared to have been converted into a presumption of incapacity which could be rebutted, only if there had been thorough capacity assessment when she signed her advance decision. The subsequent evidence of her consultant psychiatrist was insufficient, instead, according to Peter Jackson, J held that:

> "I find on the balance of probabilities that E did not have capacity at the time she signed the advance decision in October 2011. Against such an alerting background, a full, reasoned and contemporaneous assessment evidencing mental capacity to make such a momentous decision would in my view be necessary. No such assessment occurred in E's case and I think it at best doubtful that a thorough investigation at the time would have reached the conclusion that she had capacity."[656]

[655] *A Local Authority v E* [2012] EWCOP 1639.
[656] *A Local Authority v E* [2012] EWCOP 1639 at para 65.

Heywood states that the Mental Capacity Act[657] does not contain any mechanisms to ensure that a patient is mentally competent at the time of making his or her advance decision.[658] He notes that the Act does not require capacity assessments to take place when advance decisions are made. Although there are good reasons for this, that such a capacity assessment would work against the presumption of capacity (which he calls the golden thread that runs through the Mental Capacity Act), he states that a competency assessment by a witness "would certainly add a further and perhaps unwelcome layer of complexity" if the witness would have to be a trained professional with expertise in assessing capacity.[659] This would make the process of making an advance decision "more costly, time-consuming and bureaucratic".[660] This does leave many advance decisions open to legal scrutiny.

Jackson advises that "anyone who suffers from a condition which might affect their capacity would therefore be well advised not to rely on the presumption of capacity, but instead to ensure that a doctor specifically certifies that they have capacity when they make their advance decision".[661]

The advance decision must be worded specifically with reference to the treatments that are refused or will be refused in future, as well as the circumstances in which the refusals will apply.[662] If the patient is an adult, was competent and properly informed when reaching the decision, and said decision is clearly applicable to the present circumstances and there is no reason to believe that circumstances exist which the patient did not anticipate at the time when the advance decision was made and which

[657] Mental Capacity Act, 2005.
[658] Heywood R "Revisiting Advance Decision Making under the Mental Capacity Act 2005: A tale of mixed messages" (2015) 23 *Medical Law Review* 92-93.
[659] Heywood R "Revisiting Advance Decision Making under the Mental Capacity Act 2005: A tale of mixed messages" (2015) 23 *Medical Law Review* 93.
[660] Heywood R "Revisiting Advance Decision Making under the Mental Capacity Act 2005: A tale of mixed messages" (2015) 23 *Medical Law Review* 93.
[661] Jackson E *Medical Law: Text, Cases, and Materials* (2016) 271.
[662] S 24(1) Mental Capacity Act, 2005.

would have affected his or her decision had he or she anticipated them, then the advance decision is legally binding.[663]

Different authors have discussed the problematic aspect that while a person is mentally competent and writes an advance decision, that person is not yet in a position to know what it will be like to be in a mentally incompetent state. The interpretation of section 25(4)(c), whether a mentally incompetent person, for example suffering from dementia and seemingly happy, would still wish the advance decision previously made when he or she had been mentally competent to do so, to be enforced, is problematical. Would this situation count as "circumstances which P did not anticipate at the time of the advance decision and which would have affected his decision? If so, it would "almost always be possible to argue that the patients issued their advance decision in a state of relative ignorance about what it would actually be like to be incapacitated".[664] Some authors have even gone as far as to say that where there is profound incapacity the psychological continuity or psychological connectedness between the incompetent individual ("the present person") and the individual who issued the advance decision (the "past person"), might be severed, which leaves the advance decision with no authority over the incompetent person.[665] Others again believe that an advance decision should be respected because a demented person is a person with a past before the dementia set in and patient autonomy should be respected.[666] Rhoden stated that we must take both a historical and an internal point of view into consideration when confronted by unconscious or barely conscious people who are unable to express a view. "If we are to make decisions about them as persons, we must view them not only as they are in the present, but also as the persons they were – persons who had strong opinions about how their body, even when insensate, should be treated. To accomplish this, we must take both a historical and an internal point of view. "We must see the

[663] S 25 Mental Capacity Act 2005.
[664] Jackson E *Medical Law: Text, Cases, and Materials* (2016) 273-274.
[665] Buchanan A "Advance directives and the personal identity problem" (1988) 17 4 *Philosophy and Public Affairs* 283-284.
[666] Dworkin R "Autonomy and the demented self" (1986) 64 *Milbank Quarterly* 64 Suppl 2: "Medical Decision Making for the Demented and Dying".

person as she, when competent, would have imagined herself after incompetency, rather than viewing her from the outside and as she is now."[667] According to Dworkin

> "A competent person's right to autonomy requires that his past decisions, about how he is to be treated if he becomes demented, be respected even if they do not represent, and even if they contradict, the desires he has when we respect them, provided he did not change his mind while he was still in charge of his own life."[668]

4.4.3.1.1 Statutory Formalities

There is no specific prescribed statutory form, or particular formalities that have to satisfied, for an advance decision to be valid. However, refusals for life-saving treatment must be in writing and signed by the patient or by another person in the patient's presence and on the patient's direction.[669] In other words, the maker must sign the advance decision. However, should the maker be unable to sign, it is possible to ask someone else to sign on his or her behalf. The witness or witnesses must be present when the maker signs the advance decision and thereafter assign their own signatures. It is important to note that should the maker be incapable of signing the advance decision, the person who signs on his or her behalf cannot be a witness as well. It is therefore not complicated to draft an advance decision. It can be done without the help of a solicitor. The advance decision can also be written in the maker's own language that he or she can understand and does not have to include complicated legal or medical terminology. The Mental Capacity Act specifically states that the advance decision may be written in layman's terms.[670] Jackson points out that all advance decisions cannot be subjected to a "present best interests" test. A "present best interests test" would entail that an advance decision can be found to be non-binding if it does not accord with the patient's present best interests. Jackson argues that there will

[667] Rhoden NK "Litigating life and death" (1988) *Harvard Law Review* 102 375 415.
[668] Dworkin R "Autonomy and the demented self" (1986) 64 *Milbank Quarterly* 64 Suppl 2: "Medical Decision Making for the Demented and Dying" 13.
[669] S 25(6) Mental Capacity Act 2005.
[670] S2 Mental Capacity Act 2005.

be little point to the advance decisions if a present best interests test is applied, because best interest tests are in any event applied in the absence of an advance decision, and the main reason for executing an advance directive is because of the fear that future decisions will be governed by the best interests test, which might not coincide with the maker's treatment wishes.[671]

Even though the advance decision document must be in writing and signed, the Mental Capacity Act clearly states that any withdrawal or partial withdrawal need not be in writing and any alteration to the advance decision also does not need not be in writing.[672] This conforms to the idea of patient autonomy and that the patient is given free will to change his mind without restrictive formality requirements hampering any amendments or withdrawals. Even though it is not a requirement that the withdrawal or amendments need not be in writing, documented withdrawals and amendments will promote certainty.[673] The relevant sections of the Mental Capacity Act[674] read as follows:

> "(3) P may withdraw or alter an advance decision at any time when he has capacity to do so.
> (4) A withdrawal (including a partial withdrawal) need not be in writing.
> (5) An alteration of an advance decision need not be in writing".

When life-sustaining treatment is refused the English law determines that the maker needs to include a statement in his or her advance decision that the provisions of the advance decision should apply even if his or her life is at risk or shortened as a result of refusing treatment. This will indicate that the person has considered his or her decisions and understands the consequences of refusing life-sustaining treatment. In terms of

[671] Jackson E *Medical Law: Text, Cases, and Materials* (2016) 275.
[672] S24(4) and (5) Mental Capacity Act 2005.
[673] Jackson E *Medical Law: Text, Cases, and Materials* (2016) 271.
[674] Ss 24 (3)–(5) Mental Capacity Act 2005.

drafting requirements, the organisation Compassion in Dying provides free advance decision (living will) forms.[675]

4.4.3.1.2 Parameters of Advance Decisions in England

As stated above, advance decisions are only legally permissible when they amount to advance refusals of medical treatment. It is also not possible for a patient to demand specific treatments. Doctors do not grant specific treatments merely because they were requested. Doctors themselves decide on whether a treatment is medically appropriate for the patient's specific condition and symptoms. The doctors can then convey the treatment options available to the patient and the patient can decide whether or not to accept the advice and undergo the treatment or to abstain from it.

It is a prohibited clause for a patient to request assistance to end his or her life. Since assisted suicide is still illegal in England, any clauses requesting assistance in dying are prohibited in a living will.[676]

It is also not possible to refuse artificial feeding, hydration or "basic care" to keep the patient clean and comfortable. The English law compels health care workers to provide basic care. Artificial feeding and hydration are classified as basic care under the English law.

It is further unlawful to appoint a substitute decision maker in terms of an advance decision. If a person wants to appoint a substitute decision maker it has to be done by way of a lasting power of attorney.[677]

[675] Compassion in Dying "Advance Decision (Living Will) Pack" <https://compassionindying.org.uk/library/advance-decision-pack/> (accessed 24-07-2019).
[676] See discussion on assisted suicide in para
[677] See par 4.3.3.1.4

4.4.3.1.3 Advance Statements

In England it is possible to draft what is known as an advance statement. The advance statement supplements the advance decision. In the advance statement the person can provide any information that he or she thinks is important to his or her well-being, including the reasons for the advance decision, as well as a person's views on quality of life, personal values and beliefs. These are not legally binding instructions but can be considered by the ultimate decision maker. Advance requests are however relevant in the determination of a patient's best interests. Section 4(6)(a) of the Mental Capacity Act[678] states that "the person [who lacks capacity]'s past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity)", if reasonably ascertainable, must be considered in the determination of the patient's best interests.

4.4.3.1.4 Appointment of a Health Care Proxy

The Mental Capacity Act provides for the appointment of a health care proxy by means of a lasting power of attorney through which persons may appoint someone else to make health care decisions on their behalf, should they lose the capacity to decide for themselves.[679] A clause in an advance decision which provides that a patient chooses a designated person to be a substitute decision maker for treatment decisions is unlawful. The specific legislation (Mental Capacity Act) exists in terms of which a substitute decision maker can be appointed. The appointment of a substitute decision maker must be done in terms of a lasting power of attorney for health and welfare and not an advance decision.

[678] S 4(6)(a) Mental Capacity Act, 2005.
[679] S 25(2)(b) Mental Capacity Act, 2005.

4.4.3.1.5 Office of the Public Guardian

In 2007 the British Government created the "Office of the Public Guardian". This office is there to protect individuals in England and Wales who may not have the mental capacity to make certain decisions for themselves, relating to their health and finance. This office also supports and promotes decision making for people within the framework of the Mental Capacity Act.[680] If a person appoints a person to make health care decisions on his or her behalf in terms of a lasting power of attorney, this lasting power of attorney must be registered with the Office of the Public Guardian. The details of a person's attorneys can be included in the advance statement.

4.4.3.1.6 Effect of an Invalid Advance Decision

Should an advance decision be found to be invalid, in other words not meeting all the requirements of the Mental Capacity Act, then the advance decision will automatically also not be legally binding. Health care workers will in the event of a legally non-binding living will not be under any obligation to follow the stipulations contained therein. It is recommended to rather execute a new advance decision if the current document is legally non-binding.

4.4.3.2 Mental Capacity Act, 2005 Code of Practice

In the foreword to the Mental Capacity Act Code of Practice, Lord Falconer describes the importance of the Act and Code of Practice:

> "The Mental Capacity Act 2005 is a vitally important piece of legislation, and one that will make a real difference to the lives of people who may lack mental capacity. It will empower people to make decisions for themselves wherever possible, and protect people who lack capacity by providing a flexible framework that places individuals at the very heart of the decision making process. It will

[680] Jordaan L "The legal validity of an advance refusal of medical treatment in South African law (Part 2) (2011) *De Jure* 267; <www.publicguardian.gov.uk> (accessed 27-7-2015).

ensure that they participate as much as possible in any decisions made on their behalf, and that these are made in their best interests. It also allows people to plan ahead for a time in the future when they might lack the capacity, for any number of reasons, to make decisions for themselves.

The Act covers a wide range of decisions and circumstances, but legislation alone is not the whole story. We have always recognised that the Act needs to be supported by practical guidance, and the Code of Practice is a key part of this. It explains how the Act will operate on a day-to-day basis and offers examples of best practice to carers and practitioners.

Many individuals and organisations have read and commented upon earlier drafts of the Code of Practice and I am very grateful to all those who contributed to this process. This Code of Practice is a better document as a result of this input.

A number of people will be under a formal duty to have regard to the Code: professionals and paid carers for example, or people acting as attorneys or as deputies appointed by the Court of Protection. But for many people, the most important relationships will be with the wide range of less formal carers, the close family and friends who know the person best, some of whom will have been caring for them for many years. The Code is also here to provide help and guidance for them. It will be crucial to the Code's success that all those relying upon it have a document that is clear and that they can understand. I have been particularly keen that we do all we can to achieve this.

The Code of Practice will be important in shaping the way the Mental Capacity

Act 2005 is put into practice and I strongly encourage you to take the time to read and digest it."[681]

The Code of Practice is premised on the following principles:

Principle 1: "A person must be assumed to have capacity unless it is established that he lacks capacity".[682] The Mental Capacity Act Code of Practice states it clearly that the assumption should always be that the person did have the capacity when he or she made the advance decision, unless reasonable grounds exist to doubt it.
The Mental Capacity Code of Practice states that:

> "In line with principle 1 of the Act, that "a person must be assumed to have capacity unless it is established that he lacks capacity", healthcare professionals should always start from the assumption that a person who has made an advance decision had capacity to make it, unless they are aware of reasonable grounds to doubt the person had the capacity to make the advance decision at the time they made it".[683]

Principle 2: "A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success".[684]

Principle 3: "A person is not to be treated as unable to make a decision merely because he makes an unwise decision".[685]

Principle 4: "An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests".[686]

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[681] Mental Capacity Act: Code of Practice (23 October 2007) <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf> (accessed 16-07-2019).
[682] S 1(2) Mental Capacity Act, 2005.
[683] Par 9.8 Mental Capacity Act Code of Practice.
[684] S 1(3) Mental Capacity Act, 2005.
[685] S 1(4) Mental Capacity Act, 2005.
[686] S 1(5) Mental Capacity Act, 2005.

Principle 5: “Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person’s rights and freedom of action”.[687]

4.4.3.3 The National Mental Capacity Forum

The Mental Capacity Act, even with the Mental Capacity Act Code of Practice to aid the interpretation and applicability of the Act, is not without its implementation and interpretation problems. To combat the issues the so-called National Mental Capacity Forum was created to “explore the reasons that the 2005 Mental Capacity Act (MCA) had failed to meet expectations and failed to deliver the change in attitudes and behaviours that it was expected to usher in”. The work group investigates different aspects such as the principles of the MCA which are “confusing and somehow difficult to grasp”. The work group is also looking into the situation of carers who are often left out of the decision making process when decisions have to be made on behalf of a person who lacks capacity. The work group further organised a “Mental Capacity Action Day” which “brought some possible solutions to simplifying the message over the [Mental Capacity Act} itself, with presentations of excellent teaching/training initiatives.”[688]

4.4.4 Drafting, Validity, Applicability and Safekeeping of Advance Decisions

As mentioned above, there is no set form for drafting an Advance Decision and anyone can compose it, as long as it meets the validity and applicability requirements of the Mental Capacity Act. The Mental Capacity Act clearly states that an advance decision (living will) is legally binding if it is both “valid” and “applicable to the treatment”.

[687] S 1(6) Mental Capacity Act, 2005.
[688] Open Access Government “The National Mental Capacity Act Forum” (9 August 2016) <https://www.openaccessgovernment.org/national-mental-capacity-forum/27916/> (accessed 10-08-2019).

Section 26(1) states that if a decision is both valid and applicable, then "the decision has effect as if he had made it, and had had capacity to make it, at the time when the question arises whether the treatment should be carried out or continued": that is it is like a contemporaneous refusal and the person can refuse treatment for rational reasons, irrational reasons, or no reasons at all. Should a health care professional know that a patient has a valid and applicable (therefore legally binding) Advance Decision, but wishes to ignore it, it is possible to approach a court to have the living will document enforced.

Section 25(2) sets out when an advance decision will not be valid:

"An advance decision is not valid if P-

(a) has withdrawn the decision at the time when he had capacity to do so

(b) has, under a lasting power of attorney created after the advance decision was made, conferred authority on the donee (or, if more than one, any of them) to give or refuse consent to the treatment to which the advance decision relates, or

(c) has done anything else clearly inconsistent with the advance decision remaining his fixed decision."

The advance decision will thus not be valid if there is evidence to indicate that the patient has withdrawn the decision or conferred authority to a donee via a lasting power of attorney or acted in a manner which is inconsistent with the provisions contained in the advance decision.

According to Jackson it may be challenging to determine whether a person's subsequent actions are in fact "clearly inconsistent" with the advance directive. The Mental Capacity Act does not specify when the actions that invalidate the advance decision should have occurred, while the patient still had capacity or could actions after capacity was lost, invalidate the advance directive. "On the one hand, the failure to

specify when the 'clearly inconsistent' actions should take place would seem to lead to the conclusion that any inconsistent conduct should invalidate the decision. Yet, on the other hand, section 24(3) specifies that P may withdraw or alter an advance directive only 'when he has capacity to do so', so it would be odd if someone who lacks capacity could invalidate her previous advance decision simply by acting inconsistently with it".[689] The solution posed by the Code of Practice is that patients should regularly review and update their advance decisions. Recently reviewed and updated decisions will most likely more easily be found to be valid.

Even if a person's advance decision is validly executed in terms of the requirements, it will only be legally binding if it is also "applicable".

Sections 25(3) – (6) specify when an advance decision will not be applicable:

> "25(3) An advance decision is not applicable to the treatment in question if at the material time P has capacity to give or refuse consent to it.
>
> (4) An advance decision is not applicable to the treatment in question if –
>
> (a) that treatment is not the treatment specified in the advance decision
>
> (b) any circumstances specified in the advance decision are absent, or
>
> (c) there are reasonable grounds for believing that circumstances exist which P did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them."

The advance decision will only be applicable (come into operation) once the maker lacks capacity. If a person still has capacity, he or she will be able to consent or refuse medical treatment in person and the instructions contained in the advance decision will not be of any force and effect. When a person still has capacity, verbal consent overrides written instructions. That is also the situation when a person regains capacity, for the applicability of the advance directive will lapse when capacity is regained. The advance decision will also only be applicable in the specific situations stipulated in a person's advance decision. If the maker faces a different scenario to the scenarios

[689] Jackson E *Medical Law: Text, Cases, and Materials* (2016) 272.

mentioned in the advance decision, the advance decision will not be applicable. The specific treatments that a person wishes to refuse must also be stipulated. If a refusal of specific treatment was not stipulated, the treatment may still be applied.

It is furthermore important to keep change of circumstances in mind. The advance decision needs to specify the specific circumstances that the patient finds himself in and there should not be a change in circumstances since making the advance decision and the implementation thereof, as that will cause uncertainty as to whether the advance decision reflects the patient's views. If a maker's personal circumstances or medical advancements change after a person has drafted an advance decision, and if he or she had known about the changed circumstances and it would have altered the drafting of the advance decision, then the advance decision may no longer be applicable. For example, in the case of pregnancy a pregnant woman's advance decision may not specifically refer to pregnancy, thus in the situation where the maker is found to be mentally incompetent and pregnant, her advance decision will not be applicable. Jackson provides another example of a change in circumstances. Where a patient refuses the use of a specific medicine due to its intolerable side effects, but in the meantime a new version has been developed, which does not carry side effects, it may be reasonable grounds for believing that this development would have affected the patient's decision.[690]

If the maker acts contrary to the provisions of his or her advance decision, it may also indicate that he or she has changed his or her mind about specific provisions, and therefore cast doubt on the applicability of the advance decision. For example, if the maker was a Jehovah's Witness and refused blood transfusions on religious grounds in the advance decision, but later converts to Christianity, the original advance decision refusing blood transfusions on religious grounds will no longer be applicable.

[690] Jackson E *Medical Law: Text, Cases, and Materials* (2016) 272-273.

To prevent advance decisions from no longer being applicable due to changed circumstances, it is recommended to review and update the advance decision regularly, especially when the maker's health changes to reflect the maker's current wishes. If the maker's diagnosis of an illness has changed, or if his or her health status has changed, for example if she becomes pregnant, if the maker is undergoing surgery, or if new medical treatments have been developed or prescribed, then it would be recommended to update the advance decision.

The Code of Practice recommends that health care practitioners consider a number of factors when deciding whether an advance decision is applicable to the proposed treatment:

- The lapse in time from making the advance decision to enforcing same.
- Any changes in the patient's personal life which might affect the validity of the advance decision, for example a pregnancy that was not anticipated when the advance decision was made.
- Developments in medical treatment that the maker did not or could not foresee such as new medications, treatments or therapies.

The Code of Practice thus recommends that as many eventualities and changes in circumstances and possible developments in the medical field should be included, to avoid doubt as to whether the advance decision is indeed applicable to the specific circumstances, otherwise health care practitioners might decide that the advance decision is not applicable to particular circumstances. Regular updates are advised to minimise the chance that changes in circumstances might invalidate advance decisions.

Compassion in Dying recommends that any advance decisions older than two years should be renewed.[691] Living wills and advance directives made before the Mental Capacity Act of 2007 came into operation, should also be updated to ensure that they

[691] Compassion in Dying "Advance decisions (living wills) -reviewing and updating" <https://compassionindying.org.uk/library/advance-decisions-living-wills-reviewing-updating/> (accessed 10-11-2017).

conform to the provisions of the Mental Capacity Act. Should the maker move from one jurisdiction to another, or change doctors, or change a course of treatment, the advance decision should also be updated. In circumstances where a person has executed a lasting power of attorney, subsequent to the advance decision, but would wish the advance decision to take precedence over the lasting power of attorney, then the advance decision should be updated and re-executed after the execution of the lasting power of attorney for health and welfare, otherwise the lasting power of attorney will take precedence.

Compassion in Dying[692] advises the following procedure when drafting an advance decision: The maker should carefully consider what he or she would prefer in terms of medical treatment and the situations in which he or she would prefer to refuse medical treatment. It is important that the maker should speak to those close to him or her about his or her wishes so that they are aware and up to date on his or her wishes and can advocate for him or her if necessary. Thereafter an advance decision form should be completed. The advance decision form must be signed and dated by the maker in the presence of a witness who in turn also signs and dates the form. It is recommended to give a copy of the duly signed and witnessed advance decision to close family members or friends, the maker's general practitioner and anyone else involved in the maker's care. Compassion in Dying recommends that the maker makes an appointment with his or her general practitioner so that the general practitioner can explain all available treatment options and help the maker to understand the implications of decisions and choices. The general practitioner could also help with wording to express the wish to be clear and easily understood by health care professionals. Should the maker wish to refuse life-sustaining treatment, a sentence that states that refusals apply even if the

[692] The Compassion in Dying company was formed in 2007 by Dignity in Dying membership organisation that campaign for the law on assisted dying in the United Kingdom <https://compassionindying.org.uk/about-us/> (accessed 24-07-2019); <https://www.dignityindying.org.uk/about-us/> (accessed 24-07-2019). Compassion in Dying provides information on advance directives, living wills, lasting powers of attorney for health and welfare, end-of-life decision-making etc. See "Info Library" <https://compassionindying.org.uk/library/> (accessed 24-07-2019).

maker's life is at risk or shortened as a result, should be included. Compassion in Dying's Advance Decision form includes this wording.[693]

Should a disagreement arise between the family and the medical personnel regarding the enforcement of the advance decision, it would be possible for the family to call a meeting with the doctor in charge of the maker's treatment to discuss the assessed situation and the doctor's reasons for disagreeing with the advance decision. This type of meeting has been referred to as "a best interests meeting".[694]

The doctor in charge is ultimately responsible for making the final decision regarding the patient's treatment. However, the doctor should consider all the evidence available to him or her including consulting the family and health care team before making the final decision. Should the family and doctor still be in disagreement after the said meeting, the family can ask for a second opinion from a different doctor. If that does not work, a formal complaint can be issued to the specific hospital or service provider. An application can be made to Court for a declaratory order on whether the maker's advance decision is in existence, valid and applicable to a treatment.[695]
If there is any doubt about the existence, validity or applicability of a specific advance decision, medical personnel may proceed to carry out treatment or continue with treatment as the case may be, and will not incur any liability for doing so. In this respect section 26(2) of the Mental Capacity Act reads as follows:

> "A person does not incur liability for carrying out or continuing the treatment unless, at the time, he is satisfied that an advance decision exists which is valid and applicable to the treatment".

The opposite also holds true, as in the case where a person, for example the treating physician, reasonably believes that an advance decision is in existence, is valid and

[693] See Chapter 5 on the drafting of advance directives and living wills.
[694] Series H "Best interests determination: a medical perspective" in Foster C, Herring J & Doron I *The law and ethics of dementia* (2014) 89.
[695] S 26(4) Mental Capacity Act 2006.

applicable and then proceeds to withhold or withdraw treatment in terms of the advance decision, the physician will not incur any liability. The wording of section 26(3) of the Mental Capacity reads as follows:

> "A person does not incur liability for the consequences of withholding or withdrawing a treatment from P if, at the time, he reasonably believes that an advance decision exists which is valid and applicable to the treatment."

4.4.5 Specific Circumstances

Some of the most prominent specific circumstances in end-of-life decision making that are facing legal scrutiny in England, namely withdrawal of artificial feeding and hydration, assisted suicide and euthanasia are discussed below.[696]

4.4.5.1 Withholding and Withdrawing Treatment:

4.4.5.1.1 *Airedale NHS Trust v Bland*

The facts of the Bland[697] case are as follows. Anthony Bland suffered severe injuries at Hillsborough stadium when a large crowd of spectators was trampled. This event became known as the Hillsborough Stadium disaster. He was seventeen years old at the time. What happened was that scores of fans tried to enter the stadium to watch the game. This had the unfortunate result that some spectators were crushed and/or were suffocated. Ninety-six people were said to have lost their lives as a result. Mr Bland's injuries included the crushing and puncturing of his lungs which caused the oxygen supply to his brain to be interrupted, which in turn caused irreversible brain damage. When this case was heard before the House of Lords, Mr Bland had already been lying in a persistent vegetative state for over three and a half years. The doctors determined

[696] Due to the length constraint of this thesis not all the specific circumstances in which advance decisions may become relevant in terms of the English law, are discussed. See chapter 5 for a discussion on specific circumstances in terms of the South African law.
[697] *Airedale National Health Service Trust v Bland* [1993] 1 All ER 821.

that the only functioning part of his brain was the brainstem. Lord Smith in his judgement explained that from his understanding the only part of his brain which "still existed" was the brain stem, that his "chances of recovery" and "chances on improvement" were "non-existent".

Mr Bland's parents, the attending physician and independent physicians were in agreement that there was no hope of recovery. The doctors and family were of the opinion that the withdrawal of artificial nutrition and hydration and other treatments from him would be the best way forward. Therefore, NHS Trust sought a declaration that they could lawfully discontinue all life-sustaining treatment, including the withdrawal of ventilation, nutrition and hydration.

The High Court and Court of Appeal granted the declarations. The House of Lords dismissed the Official Solicitor's appeal. The House of Lords stated that where a patient lacks capacity, a doctor is duty-bound by the doctrine of necessity to treat a patient in his or her best interests, where such interests may be determined by reference to a responsible body of medical opinion. The artificial provision of nutrition and hydration was to be considered treatment. In this case responsible medical opinion held that continued treatment of this sort was not in the best interests of the patient. As such, continued treatment was no longer necessary and the doctors were freed from their duty to treat. The House of Lords held that:

> "... the principle of self-determination requires that respect must be given to the wishes of the patient, so that if an adult of sound mind refuses, however unreasonably, to consent to treatment or care by which his life would or might be prolonged, the doctors responsible for his care must give effect to his wishes, even though they do not consider it to be in his best interests to do so ... [t]o this extent, the principle of the sanctity of human life must yield to the principle of self-determination…".[698]

[698] *Airedale NHS Trust v Bland* [1993] 1 All ER 821 at 864.

4.4.5.2 Assisted Suicide and Euthanasia

As mentioned earlier, it is illegal for a person to include a request for assisted dying in an advance directive. In terms of the English common law suicide was historically regarded as self-murder and was therefore punishable by law. People who had unsuccessfully committed suicide were prosecuted and could receive a sentence of capital punishment.[699] This was the case until the Suicide Act[700] came into operation in 1961. The Suicide Act decriminalised suicide and attempted suicide. Section 1 of the Suicide Act reads as follows:

> "The rule of law whereby it is a crime for a person to commit suicide is hereby abrogated".

Jackson explains the reason for the abrogation as follows:

> "The criminal offences of suicide and attempted suicide were not abolished in order to facilitate ending one's life, but rather to protect already distressed relatives from the imposition of additional hardship, and to ensure that people who had unsuccessfully attempted suicide could seek medical help, without fearing prosecution".[701]

Section 2 of the Suicide Act determines that:

> "2 (1) A person (D) commits an offence if:
>
> a) D does an act capable of encouraging or assisting the suicide or attempted suicide of another person; and
> b) D's act was intended to encourage or assist suicide or an attempt at suicide
>
> […]

[699] Herring J *Medical law & ethics* (2008) 444.
[700] Suicide Act, 1961.
[701] E Jackson *Medical Law Texts Cases and Materials* (2016) 919-920.

(1C) An offence under this section is triable on indictment and a person convicted of such an offence is liable to imprisonment for a term not exceeding 14 years

(4) No proceedings shall be instituted for an offence under this section except by or with the consent of the Director of Public Prosecutions".

4.4.5.2.1 Media Reports: Kerrie Wooltorton

According to media reports 26 year old Kerrie Wooltorton is reportedly "the first person to have used a living will to kill herself". Wooltorton was admitted to hospital after poisoning herself, but doctors said they had no alternative but to allow her to die".[702] Wooltorton drafted her living will three days prior to her attempt to commit suicide by drinking poison. After she had drunk the poison, she phoned the ambulance service to come to collect her. Wooltorton was transported to Norfolk and Norwich University hospital, where she presented the living will document to the staff members. The doctors at the hospital said that they had no alternative but to adhere to her living will instructions and allow her to die. Her living will was drafted in explanation of her impending actions, stating that if she were to call for an ambulance it would not be because she wanted life-saving treatment, but because she did not want to die alone in her flat or in pain. At the inquest which followed the events, the fact that Wooltorton had depression came to light. She in fact had drunk poison up to 9 times in the 12 months leading up to her death, but each time the doctors had intervened to save her.

Dr Alexander Heaton, the hospital's consultant renal physician, said he had "no alternative" but to follow Wooltorton's will. He said that: "I would have been breaking the law and I wasn't worried about her suing me, but I think she would have asked, 'What do I have to do to tell you what my wishes are?'". "It's a horrible thing to have to do but I felt I had no alternative but to go with her wishes. Nobody wants to let a young lady

[702] Gabbatt, A "Doctors acted legally in a 'living will' suicide case" (1 October 2009) *The Guardian* <https://www.theguardian.com/society/2009/oct/01/living-will-suicide-legal> (accessed 25-06-2019).

die."[703] The coroner said in his verdict that the hospital was not to blame for Wooltorton's death. The coroner said that Wooltorton "had capacity to consent to treatment which, it is more likely than not, would have prevented her death. She refused such treatment in full knowledge of the consequences and died as a result".[704]

4.4.5.2.2 Case Law

4.4.5.2.2.1 *Pretty v United Kingdom*

The facts of the *Pretty v United Kingdom*[705] case are as follows. Diane Pretty (the Applicant) was suffering from motor neuron disease and paralysed from the neck down. Furthermore, she had little decipherable speech and was fed by a tube.
Under English law, it is not a crime to commit suicide; however assisting another to commit suicide is regarded as a crime.[706] Section 2(1) of the Suicide Act[707] provides as follows:

> "A person who aids, abets, counsels or procures the suicide of another, or an attempt by another to commit suicide, shall be liable on conviction on indictment to imprisonment for a term not exceeding fourteen years".

As a consequence of her illness the applicant could not commit suicide without assistance and therefore wanted her husband to provide her with the necessary assistance. Due to the criminal liability the applicant's husband would face, the applicant sought confirmation from the Director of Public Prosecutions that should her husband assist her with suicide, he would not be prosecuted. The Director of Public Prosecutions refused this request, and Pretty instituted legal proceedings to challenge the decision.

[703] Gabbatt, A "Doctors acted legally in a 'living will' suicide case" (1 October 2009) *The Guardian* <https://www.theguardian.com/society/2009/oct/01/living-will-suicide-legal> (accessed 25-06-2019).
[704] Gabbatt, A "Doctors acted legally in a 'living will' suicide case" (1 October 2009) *The Guardian* <https://www.theguardian.com/society/2009/oct/01/living-will-suicide-legal> (accessed 25-06-2019). See critique of the Wooltorton case in Shaw D "A direct Advance on Advance Directives" (2012) 26 5 Bioethics: 268.
[705] *R (Pretty) v DPP* [2002] 1 AC 800; *Pretty v UK* [2002] 35 EHRR 1.
[706] S 2(1) Suicide Act 1961.
[707] S 2(1) Suicide Act 1961.

The House of Lords also refused this request and Pretty was left to appeal to the European Court of Human Rights.

In a unanimous judgment, the seven judges of the Strassbourg Court, found Pretty's application under articles 2, 3, 8, 9 and 14 of the European Convention on Human Rights admissible, but did not find any violation of the Convention. Article 2 of the convention provides:

> "*Right to life*
>
> 1. Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.
>
> 2. Deprivation of life shall not be regarded as inflicted in contravention of this article when it results from the use of force which is no more than absolutely necessary:
>
> (a) in defence of any person from unlawful violence;
>
> (b) in order to effect a lawful arrest or to prevent the escape of a person lawfully detained;
>
> (c) in action lawfully taken for the purpose of quelling a riot or insurrection."

In an unanimous judgment the Strassbourg Court found that “no right to die, whether at the hands of a third person or with the assistance of a public authority, can be derived from article 2 of the European Convention on Human Rights”.[708] The Court found that article 2 (the right to life) is “first and foremost a prohibition on the use of lethal force or other conduct which might lead to the death of a human being and does not confer any right on an individual to require a State to permit or facilitate his or her death”.[709] Article 8 of the European Convention of Human Rights reads as follows:

> “1. Everyone has the right to respect for his private and family life, his home and his correspondence.

[708] *Pretty v United Kingdom* (2002) 35 EHRR 1 at 40.
[709] *Pretty v United Kingdom* (2002) 35 EHRR 1 at 45.

2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others".

The applicant argued that the right to self-determination was "most explicitly recognised and guaranteed" in article 8. She argued that the right to self-determination "encompassed the right to make decisions about one's body and what happened to it" and "included the right to choose when and how to die and that nothing could be more intimately connected to the manner in which a person conducted her life than the manner and timing of her death."[710] The applicant argued further that the Government must have "particularly serious reasons for interfering with such an intimate part of her private life", but had failed to show that such interference was justified and that no consideration had been given to her personal circumstances.[711]

The European Court of Human Rights found that the notion of personal autonomy is an important principle underlying article 8.[712] The court further stated that "the ability to conduct one's life in a manner of one's own choosing may also include the opportunity to pursue activities perceived to be of a physically or morally harmful or dangerous nature for the individual concerned" and the fact that death was not the intended consequence of these activities could not be decisive.[713] The court said that medical treatment without consent would "interfere with a person's physical integrity in a manner capable of engaging the rights protected under article 8(1)".[714]

[710] *Pretty v United Kingdom* (2002) 35 EHRR 1 at 58.
[711] *Pretty v United Kingdom* (2002) 35 EHRR 1 at 59.
[712] *Pretty v United Kingdom* (2002) 35 EHRR 1 at 61.
[713] *Pretty v United Kingdom* (2002) 35 EHRR 1 at 62.
[714] *Pretty v United Kingdom* (2002) 35 EHRR 1 at 62 & 63.

The court was not prepared to exclude that the fact that the applicant is prevented by law from exercising her choice to avoid what she considers an undignified and distressing end to her life, constitutes an interference with her right to respect for private life as guaranteed under article 8(1) of the Convention. The court however found in the analysis of article 8(2) that such interferences with Pretty's right to respect for private life under article 8, may be justified as “necessary in a democratic society for the protection of the rights of others” and therefore concluded that there had been no violation of article 8.[715]

4.4.5.2.2.2 *R (Purdy) v Director of Public Prosecutions*[716]

In this case the House of Lords found that Debbie Purdy, a multiple sclerosis patient, successfully argued that it is a breach of her human rights not to know whether her husband will be prosecuted if he accompanies her to the Swiss euthanasia clinic Dignitas. The House of Lords concluded that article 8 of the European Convention on Human Rights stretched at least from the “delivery suite to the death bed” and found that the Director of Public Prosecutions was acting in breach of Purdy’s rights under article 8 of the European Convention on Human Rights by failing to publish guidance on whether it would be likely that her husband would be prosecuted if he were to assist her to travel to Switzerland for an assisted suicide.

4.4.5.2.2.3 *R (Nicklinson) v Ministry of Justice* [717]

The facts of the case are as follows: In 2004 Mr Nicklinson suffered a stroke which left him almost completely paralysed with so-called “locked-in syndrome”. He was unable to speak and carry out any physical functions on his own except limited movement of his eyes and head. He could communicate by blinking at a board with letters, and later on

[715] *Pretty v United Kingdom* (2002) 35 EHRR 1 at 78.
[716] *R (Purdy) v Director of Public Prosecutions* [2009] UKHL 45, [2010] 1 AC 345
[717] *Nicklinson, R (on the application of) v Ministry of Justice* [2012] EWHC.

obtained use of an eye-blink computer. He was in regular physical and mental pain, unable to eat normal food and was effectively housebound.

Nicklinson wanted to die and made a living will in 2007 requesting that all medical treatment, save pain relief, be terminated. He also stopped taking any medication intended to prolong his life. As in the case of *Pretty* and *Purdy*, due to his disabilities, Nicklinson was unable to kill himself without assistance other than abstaining from food and water. He however did not want to put his family through that pain and wanted a more humane and dignified exit from the world. Therefore, Nicklinson wanted a third party to kill him by injecting him with a lethal drug. However, under English law voluntary euthanasia is viewed as murder. Even if the third party only assisted in the suicide, the assistance would amount to an offence under section 2(1) of the Suicide Act[718], namely encouraging and assisting a person to commit suicide.

Nicklinson therefore approached the High Court for a declaratory order that either the provision of medical assistance to end his life would not be unlawful because the third party would be able to rely on the common law defence of necessity for justification, or that the law on murder and assisted suicide was in breach of his rights under articles 2 and 8 of the European Convention on Human Rights. The article 2 claim was refused permission to proceed, and therefore he proceeded on the common law defence of necessity and article 8 grounds.

Dr Nitschke had invented a machine which could be loaded with a lethal drug, and thereafter digitally activated by Nicklinson, using an eye-blink computer with a specific pass phrase. Nicklinson was prepared to consider assisted suicide through use of Dr Nitschke's machine, but preferred voluntary euthanasia. The Divisional Court dismissed the claim.

In summary the essential issues were:

[718] Suicide Act, 1961.

1. Was voluntary euthanasia a possible defence to murder; and
2. Alternatively, was section 2(1) incompatible with article 8 in obstructing Mr Nicklinson from exercising a right to receive assistance to commit suicide?

On the first issue, Lord Judge Toulson examined the *Pretty* judgments[719] of the House of Lords and European Court of Human Rights and found that it would be wrong for the court to hold that article 8 required voluntary euthanasia to afford a possible defence to murder, as this went far beyond anything which the House of Lords had said previously, furthermore such a finding would be inconsistent with previous domestic and Strassbourg judgments and would usurp the proper role of Parliament.

On the second issue, namely whether section 2(1) of the Suicide Act was incompatible with article 8, Toulson LJ found that the matter had already been determined at the highest level. Toulson LJ further found that even if it were open to the court to consider this issue afresh, he would reject the claim on the ground that in the domain of assisted suicide, member States enjoy a wide margin of appreciation and that in the United Kingdom specifically; assisted suicide is a matter for determination by Parliament.

Following the pronouncement of the judgment, Mr Nicklinson refused food and died of pneumonia on 22 August 2012.[720]

Nicklinson's wife, Jane Nicklinson, joined by Paul Lamb, a motor accident victim who was left paralysed and in great pain by the accident, appealed to the European Court of Human Rights[721]. The submission was made that the Strassbourg court found in *Pretty v United Kingdom*[722] that exceptional cases may exist in which an absolute ban on assisted suicide would be disproportionate. The Court of Appeal however disagreed with this submission, and found that the Strassbourg court in the *Pretty* case was not

[719] *R (Pretty) v DPP* [2002] 1 AC 800; *Pretty v United Kingdom* (2002) 35 EHRR 1.
[720] Boseley S "Tony Nicklinson dies after losing 'right to die' legal battle" (22 August 2012) *The Guardian* <https://www.theguardian.com/uk/2012/aug /22/tony-nicklinson-dies-right-to-die> (accessed 13-08-2019).
[721] *Nicklinson & Lamb v United Kingdom* 2478/15 [2015] ECHR 709.
[722] *Pretty v United Kingdom* (2002) 35 EHRR 1 at 76.

seeking to suggest that a blanket ban was disproportionate or that a prosecution may sometimes infringe article 8 rights and furthermore said that this is an area within Parliament's margin of appreciation, and therefore decided that they were bound by the decision in *Pretty* to conclude that the current prohibitions on assisted suicide and euthanasia were not a disproportionate interference with article 8 rights. The European Court of Human Rights held that the question on whether the interference with article 8 rights is justified, is for each member state to decide as there is no European consensus on this matter.

4.4.5.2.2.4 *R (Conway) v Secretary of State for Justice*

The Noel Conway assisted suicide case has also attracted a lot of media attention.[723] Conway applied for a judicial review of the ban on assisted suicide. He lodged an application that the ban on assisted dying, contained in section 2(1) of the Suicide Act 1961, be declared incompatible with his rights under article 8 of the European Convention on Human Rights.

He was 67 years of age, at the time of the application, and is suffering from motor neuron disease described by the Supreme Court as "a neurological disease which attacks the nerve cells responsible for voluntary muscle movement". He is wheelchair bound and breathes with a non-invasive ventilation machine for about 23 hours per day. Conway argued that the ban on assisted suicide prevents him from ending his own life without protracted pain. Conway wanted to have the opportunity to be granted control over his death. Once it was predicted that he had less than six months left to live, he would have wanted a medical professional to be allowed prescribe him medication which he himself could choose to take "to bring his life to an end when and where he

[723] In *R. (on the application of Conway) v Secretary of State for Justice* [2018] EWCA Civ 1431. Bowcott O "Terminally ill former lecturer challenges UK ban on assisted dying" (21 March 2017) <https://www.theguardian.com/society/2017/mar/21/terminally-ill-former-lecturer-challenges-uk-ban-on-assisted-dying > (accessed 19-07-2019).

would like". Conway was unsuccessful in his appeals to the High Court and Supreme Court of Appeal.

Section 2 of the 1961 Suicide Act makes this illegal and punishable, for anyone to aid or abet or counsel or procure the suicide of another. Section 2(1) of the Suicide Act[724] provides as follows:

> "A person who aids, abets, counsels or procures the suicide of another, or an attempt by another to commit suicide, shall be liable on conviction on indictment to imprisonment for a term not exceeding fourteen years."

Mr Conway argued that the current law is an unjustifiable interference with the right to respect for private life under the European Convention on Human Rights. The three Supreme Court judges found that it was open to them to declare the current law was incompatible with the convention, and leave it to Parliament to decide what to do about it.

The Supreme Court found that "Mr Conway could bring about his death in another way, by refusing consent to the continuation of his NIV [non-invasive ventilation]. That is his absolute right at common law. Currently, he is not dependent on continuous NIV, so could survive for around at least one hour without it. But once he becomes dependent on continuous NIV, the evidence is that withdrawal would usually lead to his death within a few minutes, although it can take a few hours or in rare cases days. The evidence from the specialist in palliative care who is looking after him is that medication can be used to ensure that he is not aware of the NIV being withdrawn and does not become uncomfortable and distressed."[725] Mr Conway was not prepared to accept that withdrawing his NIV while being kept under heavy sedation, would amount to a dignified death. The court summarised his reasons as follows: "He does not know how he would feel, whether he would experience the drowning sensation of not being able to breathe, whether he would be able to hear his family and feel their touch. Taking lethal medicine

[724] S 2(1) Suicide Act 1961.
[725] In *R. (on the application of Conway) v Secretary of State for Justice* [2018] EWCA Civ 1431 para 4.

would avoid all these problems. In his view, which is shared by many, it is his life and he should have the right to choose to end it in the way which he considers most consistent with his human dignity." The court stated that the difference between letting die and actively bringing about someone's death "…has been central to the common law for centuries. Some argue that to depart from that distinction is to cross a dangerous Rubicon. Some argue that the distinction is morally and practically defensible." The court referred to the *Pretty*[726] and *Nicklinson*[727] judgements and came to the conclusion that there is no European consensus on the matter and that under the United Kingdom's constitutional arrangements, only Parliament could change the law. However "the Supreme Court could, if it thought right, make a declaration that the law was incompatible with the Convention rights, leaving it to Parliament to decide, what, if anything to do about it. The questions for the court would therefore be two-fold: (1) Is the hard and fast rule banning all assistance to commit suicide a justified interference with the Convention rights of those who wish for such assistance? (2) If it is not, should this court make a declaration to take effect? In particular, is it appropriate to make such a declaration in this case? These are questions upon which the considered opinions of conscientious judges may legitimately differ. Indeed, they differ amongst the members of this panel."[728] The court said the ultimate question was whether "the prospects of Mr Conway's succeeding in his claim before this court are sufficient to justify our giving him permission to pursue it, with all that that would entail for him, for his family, for those on all sides of this multi-faceted debate, for the general public and for this court. Not without some reluctance, it has been concluded that in this case those prospects are not sufficient to justify giving permission to appeal."[729]

[726] *Pretty v United Kingdom* (2002) 35 EHRR 1 at para 65: "The very essence of the Convention is respect for human dignity and human freedom".
[727] *Nicklinson v United Kingdom* (2015) 61 EHRR 97.
[728] In *R. (on the application of Conway) v Secretary of State for Justice* [2018] EWCA Civ 1431 para 7.
[729] In *R. (on the application of Conway) v Secretary of State for Justice* [2018] EWCA Civ 1431 para 8.

4.4.5.2.3 Assisted Dying Bill

On 11 September 2015 the House of Commons in a majority vote rejected a private member (Rob Harris)'s Assisted Dying Bill. The aim of the Bill, originally put forward by Lord Falconer, was to ensure a framework to give terminally ill individuals choice over their end-of-life care by for example legalising voluntary euthanasia. 118 Members voted for the Bill and 330 voted against the Bill. One would have thought that the considerable margin would have served as an indication that another Assisted Dying Bill will not be debated any time soon. However, Member of Parliament Nick Boles called for a debate on the current legal position pertaining to assisted dying. The debate took place on 4 July 2019. We await to see whether further action will be taken.

4.4.5.2.4 The British Royal College of General Practitioners

The British Royal College of General Practitioners has recently published the following statement:

> "The Royal College of General Practitioners will consult its 53,000 members as to what its stance should be on whether there should be a change in the law on assisted dying.
> The decision was made by the College's governing Council, which met today.
>
> The College last consulted its members on the issue in 2013. The result, announced in February 2014, was that the College should not change its stance, and as such, its current position is that it is opposed to any change in the law on assisted dying.
>
> Further details of how we consult will be made public in due course.
>
> Professor Helen Stokes-Lampard, Chair of the RCGP, said: 'Assisted dying is an incredibly emotive issue that polarises opinions. It has been nearly six years

since we asked our members as to whether we should support a change in the law on assisted dying – since then, it is possible that views within our membership have shifted. As such, RCGP Council has decided that the time is right to conduct this consultation, and we will be issuing further details of how we will do this in due course'."[730]

4.4.5.2.5 Lady Hale, Hardtalk interview[731]

In an interview on BBC Hardtalk the interviewer Stephen John Sackur discussed pressing legal matters of relevance to this thesis with Lady Hale, the President of the United Kingdom Supreme Court. On the question of assisted suicide, the interviewer said:

> "I want to bring you now to one extraordinarily complicated morally and ethically loaded question and that is about assisted dying and assisted suicide some people call it. You again personally on the Supreme Court have faced some very difficult cases. I'm thinking of the Paul Lamb case, the Tony Nicklinson case. These are men, different cases, but desperate to be allowed to die, in grave physical circumstances. The Court has not given them what they wanted: assisted suicide, the right to die because you are guided by law and you concluded that it would not be legal, should the law change?"

Lady Hale answered:

> "There is an Act of Parliament that makes it a criminal offence to help somebody to commit suicide. I would draw a very clear distinction incidentally between assisted suicide and euthanasia, killing somebody, however much they would want to be killed. I think it is a very important distinction. There is an Act of Parliament and an Act of Parliament is the law, so we could never have changed

[730] RCGP "RCGP to consult members on assisted dying" (22 June 2019) <https://www.rcgp.org.uk/about-us/news/2019/june/rcgp-to-consult-members-on-assisted-dying.aspx> (accessed 22-06-2019)

[731] HARDtalk interview "President of the UK Supreme Court – Lady Hale" (10 July 2019) <https://www.bbc.co.uk/sounds/play/w3csy9dg> (accessed 10-7-2019).

> it. I was one of the two Justices in the Nicklinson case who said that there is the right to choose the time and manner of your own death, which is part of the right to respect for private life, which is protected under the European Convention of Human Rights. The question is therefore whether the absolute ban on anybody helping you, is a proportionate interference with that right. Lord Kerr and I thought that it was not, and that there was a solution that could be devised that would make it acceptable and protect the people who need to be protected. So that was my view."

The interviewer remarked that the legal situation regarding assisted suicide "is fascinating and complex" and continued by saying: "I want to end off with one extraordinary quote from a fellow Supreme Court Justice sitting with you on the bench, Lord Sumption. He recently said this of the assisted dying debate: 'I think the law should continue to criminalise assisted suicide, but I also think that the law should be broken from time to time. It is an untidy compromise but I don't believe there is not always a moral obligation to obey the law and ultimately it is up to each person to decide.' Would you go along with that?"
Lady Hale responded: "No".
Interviewer: "Because?"
Lady Hale: "I believe the law should be respected. But I believe the law should attempt to accommodate the different moral viewpoints that people will have about the situation that we are talking about. So that those who need to be protected, are protected, and those who are genuinely autonomous, able to make their own decisions without pressure, without anybody forcing them what to do what they want to do so that they can do what they want to do."

In summary, England has a legal framework for advance decisions in place. However, lots of uncertainties pertaining to the enforcement of advance decisions remain. The current situation pertaining to assisted suicide in England is very unsatisfactory, as neither the Courts nor Parliament have to date taken a stance to start the process to

decriminalise assisted suicide. The Supreme Court had the opportunity to grant a declaration of incompatibility in the *Conway*[732] case, but did not think that on the facts of the case, it was appropriate in the circumstances. However, the question of assisted dying remains an important one that has to be debated by the courts or Parliament, as dying is part of every person's life. As the Supreme Court noted in the *Conway* case "No-one doubts that the issue [of assisted dying] is of transcendent public importance. It touches us all. We all have to experience the death of people about whom we care. We all have to contemplate our own death".

The Canadian legal framework regarding living wills is discussed in the next section.

4.5 Canada

4.5.1 Current Legal Position

Canada has become a very culturally diverse nation with increasing heterogeneity with respect to ethnic origin, languages, health practices and core beliefs. Such a culturally sensitive country requires culturally sensitive end-of-life care. The underlying values and preferences of minority groups related to death and dying need to be carefully considered.[733] In the End-of-Life Decision-Making Report by the Royal Society of Canada Expert Panel on End-of-Life Decision-Making the above was mentioned and the focus was on demographic changes in Canada. The report found that Canadians are currently living longer and contracting more chronic diseases than has been the case historically. The report further stated that the age group over 65 constitutes the fastest growing segment of the Canadian population and consumes the largest amount of health care resources, specifically in terms of physician visits, pharmacy bills and

[732] In *R. (on the application of Conway) v Secretary of State for Justice* [2018] EWCA Civ 1431 at para 8.
[733] Schüklenk U, Van Delden JMM, Downie J, AMS Mclean, Upshur R and Weinstock D "End-of-Life Decision-Making in Canada: The Report by the Royal Society of Canada Expert Panel on End-of-Life Decision-Making" (2011) *Bioethics* 25 No SI 1-73 17.

homecare resources.[734] The report also noted that in Canada there have been a number of developments in the field of assisted suicide with highly publicised high-profile cases.[735]

As a result of the culturally diverse ageing population, the use of advance directives in Canadian medical decision making will become even more relevant in future. In Canada there is currently no federal legislation on advance directives, however, legislation on advance directives is found in almost all the different jurisdictions.[736] As a result, there are noticeable variations among provinces and territories with regard to the content and processes to be followed in respect of advance directives. Since the advance directive legislation has not been harmonised, and no federal legislation exists, inconsistencies in terms of terminology exist. Authors criticise the fact that there are no standard definitions pertaining to advance directives.[737] The organisation Dying with Dignity Canada has resolved the confusion which exists as a result of ambiguous definitions of advance directives by using the term "advance requests" to describe documents pertaining to requests for medical assistance in dying. The semantic emphasis has therefore shifted from "advance directives" to "advance requests". Dying with Dignity Canada is campaigning for a federal law on advance requests, a consistent meaning under the Federal Criminal Code and a standard form for the advance request document.[738] As stated above many variations of the advance directive document currently exist depending on Province and Territory. In general Canadian health care workers are obliged to follow the instructions contained in advance directives provided the patient lacks capacity, furthermore provided the advance directive is applicable to

[734] Schüklenk U, Van Delden JMM, Downie J, AMS Mclean, Upshur R and Weinstock D "End-of-Life Decision-Making in Canada: The Report by the Royal Society of Canada Expert Panel on End-of-Life Decision-Making" (2011) *Bioethics* 25 No SI 1-73 16.
[735] Schüklenk U, Van Delden JMM, Downie J, AMS Mclean, Upshur R and Weinstock D "End-of-Life Decision-Making in Canada: The Report by the Royal Society of Canada Expert Panel on End-of-Life Decision-Making" (2011) *Bioethics* 25 No SI 1-73 5.
[736] Irvine JC, Osborne PH & Shariff MJ *Canadian Medical Law An introduction for Physicians and other Health Care Professionals* 4th Ed (2013) 740-741.
[737] Irvine JC, Osborne PH & Shariff MJ *Canadian Medical Law An introduction for Physicians and other Health Care Professionals* 4th Ed (2013) 677.
[738] Shanaaz Gokool on behalf of Dying with Dignity Canada "A path toward Advance Requests for Assisted Dying" Online Webinar 27 Nov 2018.

the current medical situation of the patient and provided the patient is not requesting illegal or a medically futile treatment.[739] The next section focuses on the terminology of advance directives in Canada.

4.5.1.1 Definition of a Living Will in terms of Canadian Law

"Advance directives" have been defined as "directions given by a competent individual concerning what and/or how and/or by whom decisions should be made in the event that, at some time in the future, the individual becomes incompetent to make health care decisions".[740] The advance directives therefore only come into operation once the maker, who was competent at the time of making the advance directive, is found to be incompetent to make his own medical decisions.

Irvine *et al* describe an "advance directive" as

> "a generic term that refers to any directions given by a competent individual for future personal health care decision making should that individual become incompetent or lack capacity to give those directions. Other terms that have been used to describe an advance directive include: Personal Directive; Health Care Directive; Living Will; Medical Directive; Personal Care Directive; or Advance Care Plan".[741]

As Irvine pointed out varying terms are used to describe advance directives in the different Canadian provinces and territories. Terminology used include, for example, "advance healthcare directive" (Newfoundland),[742] "health care directive" (Prince

[739] JC Irvine, PH Osborne & MJ Shariff *Canadian Medical Law An introduction for Physicians and other Health Care Professionals* 4th Ed (2013) 677.
[740] Schüklenk U, Van Delden JMM, Downie J, AMS Mclean, Upshur R and Weinstock D "End-of-Life Decision-Making in Canada: The Report by the Royal Society of Canada Expert Panel on End-of-Life Decision-Making" (2011) *Bioethics* 25 No SI 1-73 7.
[741] Irvine JC, Osborne PH & Shariff MJ *Canadian Medical Law An introduction for Physicians and other Health Care Professionals* 4th Ed (2013) 677-678.
[742] Advance Health Care Directives Act, 1995.

Edward Island,[743] Manitoba,[744] and Saskatchewan),[745] "mandate" (Quebec),[746] "personal directive" (Alberta),[747] "representation agreement" (British Columbia)[748] and Ontario refers to "wishes"[749] and "power of attorney for personal care".[750] A few provinces do not have legislation on advance directives specifically, for example New Brunswick and Nunavut.[751]

Irvine *et al* describe the problematic aspects pertaining to advance directives in Canada, as follows:

> "The Advance Directive may refer to values and personal, quality of life goals. Most Advance Directives, however, focus on the consent to or refusal of medical treatments, or the instructions for care relating to specific health conditions. Unless the Advance Directive specifically refers to the particular treatment decision facing the patient, the Advance Directive can be ignored by health care provider(s). When in written form, the Advance Directive is a legal document, however the language used in the document is not standardized across Canada and lack of clarity in the document can sometimes be problematic. Furthermore, while some jurisdictions do recognize oral Advance Directives; other jurisdictions only recognize written Advance Directives that meet specific legislated requirements."[752]

A "living will" is sometimes referred to as a "first generation advance directive" as the content tends to focus predominantly on the refusal of life-prolonging medical

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[743] Consent to Treatment and Health Care Directives Act, 1996.
[744] Health Care Directives Act, 1993.
[745] Health Care Directives and Substitute Health Care Decision Makers Act, 1997.
[746] Quebec Civil Code, 1991.
[747] Personal Directives Act, 1996.
[748] Health Care (Consent) and Care Facility (Admission) Act, 1993 and Representation Agreement Act, 1996.
[749] Health Care Consent Act, 1996 and Advocacy Act, 1992.
[750] Substitute Decisions Act, 1992.
[751] Irvine JC, Osborne PH & Shariff MJ *Canadian Medical Law An introduction for Physicians and other Health Care Professionals* 4th Ed (2013) 720-721.
[752] Irvine JC, Osborne PH & Shariff MJ *Canadian Medical Law An introduction for Physicians and other Health Care Professionals* 4th Ed (2013) 677-678.

treatments in end-of-life scenarios and is therefore not as broad as the second generation advance directive. The terms are often however still unclear and a person referring to a living will may actually mean to refer to the broader advance directive. However, the term "living will" does not appear in any Canadian Statutes, only the term "advance directive" appears in said Statutes.[753]

4.5.1.2 Nature and Scope of Advance Directives in Canadian Law

Canadian law recognises two types of advance directives that exist namely "instructional directives" and "proxy directives". These two types of directives can also be combined in one single document.

4.5.1.2.1 The Instructional Directive

The instructional directive is a document wherein the maker conveys particular instructions about his or her medical treatment, specific health care decisions and/or personal care to take effect when he or she is no longer able to personally convey these instructions at a future stage.[754] The Canadian law does not prescribe a set format or specific wording to be used.[755]

It is possible that the instructional directive be limited to instructions regarding end-of-life treatment (in terms of the narrow reading of a living will document). Other instructional directives can be more detailed describing different medical circumstances or scenarios and treatment choices (the broader meaning). It can even include the maker's goals and important personal values for end-of-life situations. Patients can include personal

[753] Irvine JC, Osborne PH & Shariff MJ C*anadian Medical Law An introduction for Physicians and other Health Care Professionals* 4th Ed (2013) 680.
[754] Irvine JC, Osborne PH & Shariff MJ *Canadian Medical Law An introduction for Physicians and other Health Care Professionals* 4th Ed (2013) 679.
[755] Irvine JC, Osborne PH & Shariff MJ *Canadian Medical Law An introduction for Physicians and other Health Care Professionals* 4th Ed (2013) 679.

wishes, preferences, beliefs, goals, values and other instructions regarding the different medical scenarios mentioned in the directive.[756]

4.5.1.2.2 The Proxy Directive

The proxy directive is a type of advance directive wherein the maker may appoint a third party.[757] The terms used by the different Provinces and Territories differ for example "proxy" (Manitoba, Prince Edward Island, Saskatchewan and Yukon); "substitute decision-maker" (Newfoundland and Labrador), or a "personal care agent" (Alberta, Northwest Territories); a "representative" (British Columbia) or a "delegate" (Nova Scotia). These are all terms for a proxy who is appointed by the maker to take decisions regarding the maker's future medical treatments. The proxy will only act in circumstances where the maker is incompetent or incapable of personally making the necessary decisions.[758]

In most Provinces where advance directive legislation exists, provision for proxy directives are included. However provisions for instructional directives are not always included.[759] The proxy is obliged to follow the maker's instructions that were given when the maker was still competent. However, if said instructions do not exist (where an instructional directive was not given) or if the instructions given are not relevant to the specific situation, the proxy will make a decision based on what the proxy believes the maker's instructions would have been in the given situation. If the proxy does not have

[756] Schüklenk U, Van Delden JMM, Downie J, AMS Mclean, Upshur R and Weinstock D "End-of-Life Decision-Making in Canada: The Report by the Royal Society of Canada Expert Panel on End-of-Life Decision-Making" (2011) *Bioethics* 25 No SI 1-73 18. JC Irvine, PH Osborne & MJ Shariff *Canadian Medical Law An introduction for Physicians and other Health Care Professionals* 4th Ed (2013) 679.
[757] Irvine JC, Osborne PH & Shariff MJ *Canadian Medical Law An introduction for Physicians and other Health Care Professionals* 4th Ed (2013) 679.
[758] Schüklenk U, Van Delden JMM, Downie J, AMS Mclean, Upshur R and Weinstock D "End-of-Life Decision-Making in Canada: The Report by the Royal Society of Canada Expert Panel on End-of-Life Decision-Making" (2011) *Bioethics* 25 No SI 1-73 18. JC Irvine, PH Osborne & MJ Shariff *Canadian Medical Law An introduction for Physicians and other Health Care Professionals* 4th Ed (2013) 679.
[759] Irvine JC, Osborne PH & Shariff MJ *Canadian Medical Law An introduction for Physicians and other Health Care Professionals* 4th Ed (2013) 679.

knowledge of what the maker's instructions would have been, the proxy will have to decide the course of action based on the principle of the best interests of the maker.[760]

In Provinces and Territories where there is legislative provision for the appointment of a proxy, the proxy appointed by the maker is usually the first listed substitute decision maker. If however, there is no legislative provision for the appointment of a proxy by the maker, the substitute decision maker will be one of a number of persons in close relationship to the patient and ranked in hierarchical order for example spouse, parent or child. If, in jurisdictions that allow for the appointment of a health care proxy, the appointed proxy is unable or unwilling to act on behalf of the maker, another substitute decision maker can be appointed.[761] In other jurisdictions where there are no legislative provisions for the appointment of a proxy by the maker, or if the maker has elected not appointed a proxy, then the substitute decision maker will be one of the listed persons described terms of their close relationship to the patient for example a spouse, child, parent. The substitute decision maker has the power to consent to or refuse treatment for the patient. The legislation spells out the principles that the substitute decision maker must follow for granting or refusing consent. The health care provider must rely on the substitute decision maker's decision unless a court (or in Ontario the Consent and Capacity Board) finds otherwise. Court decisions can be appealed to a higher court and board decisions can be appealed to court.

It is furthermore possible to draft a "Power of Attorney for Personal Care", also known as an "Enduring Power of Attorney for Personal Care" or a "Durable Power of Attorney for Personal Care".[762] This document is "enduring" or "durable" because it continues to be in full force and effect even when the signee becomes mentally incompetent. The document is usually drafted by a lawyer and sets the boundaries of the appointed

[760] Irvine JC, Osborne PH & Shariff MJ *Canadian Medical Law An introduction for Physicians and other Health Care Professionals* 4th Ed (2013) 679.
[761] Irvine JC, Osborne PH & Shariff MJ Cana*dian Medical Law An introduction for Physicians and other Health Care Professionals* 4th Ed (2013) 680.
[762] Irvine JC, Osborne PH & Shariff MJ *Canadian Medical Law An introduction for Physicians and other Health Care Professionals* 4th Ed (2013) 680.

Attorney for Personal Care's decision making powers.[763] The competent person with the necessary capacity has to sign the document. The appointed Attorney for Personal Care can then make the necessary decisions regarding the signatory's personal care any time that the signatory is incapable or incompetent to make his or her wishes known. The terms "personal care" and "personal matter" are described in legislation.[764] The Power of Attorney for Personal Care is not be confused with the standard Power of Attorney used to regulate financial affairs, property and administration thereof.[765]

4.5.2. Historical Development: Informed Consent

As indicated in chapter 1 paragraph 1.2.2 the concept of a "living will" was first proposed in the United States as a result of the technological advances in medical care, which made it possible to prolong life artificially. An attorney from Illinois, Luis Kutner, coined the term "living will" in an article in the *Indiana Law Review* in 1969.[766] The concept of a living will therefore has its origin in the United States of America. Thereafter in 1995 an article was published in the *Journal of the American Medical Association* wherein the authors suggested the use of "advance directives" to move the focus of decision making from the doctor to the patient.[767] The advance directive was deemed an appropriative solution for patients who wanted to retain autonomy even when mentally incapacitated.[768] After the publication of the article various extensive studies were conducted regarding advance directives. Thereafter advance directives became more

[763] Irvine JC, Osborne PH & Shariff MJ *Canadian Medical Law An introduction for Physicians and other Health Care Professionals* 4th Ed (2013) 680.
[764] Irvine JC, Osborne PH & Shariff MJ *Canadian Medical Law An introduction for Physicians and other Health Care Professionals* 4th Ed (2013) 681.
[765] Irvine JC, Osborne PH & Shariff MJ Canadian Medical Law An introduction for Physicians and other Health Care Professionals 4th Ed (2013) 681.
[766] See discussion chapter 1 para 1.2.2. L Kutner "Due Process of Euthanasia: The Living Will, A Proposal" (1969) 44 (4) *Indiana Law Journal* 539.
[767] Cook DJ, Guyatt GH, Jaeschke R, Reeve J, Spanier A, King D, Molloy DW, Willan A & Streiner DL "Determinants in Canadian Health Care Workers of the Decision to Withdraw Life Support from the Critically Ill. Canadian Critical Care Trials Group" (1 Mar 1995) 273(9) *Journal of the American Medical Association* 703-708.
[768] Irvine JC, Osborne PH & Shariff MJ *Canadian Medical Law An introduction for Physicians and other Health Care Professionals* 4th Ed (2013) 676.

known and accessible with various templates obtainable over the internet.[769] Despite these developments, only a small percentage of the Canadian population makes use of advance directives.[770]

The prerequisite for any medical treatment is informed refusal or informed consent. To enable a patient to make a valid advance directive, the patient needs to in a position to provide informed consent or informed refusal. An individual is said to have the necessary legal capacity to validly consent or refuse medical treatment or make an advance directive should the individual be able to understand the nature and effect of the proposed treatment, understand the alternatives available, and is able to grasp the consequences of requesting of refusing the treatment.[771] When a person moves in and out of lucidness, for example in a terminal illness situation, it is possible for the person to have capacity to consent or refuse treatment during lucid intervals.

In the *Malette v Schulman*[772] case the court gave a description of informed consent as follows:

> "The right to self-determination which underlies the doctrine of informed consent also obviously encompasses the right to refuse medical treatment. A competent adult is generally entitled to reject a specific treatment or all treatment, or to select an alternate form of treatment, even if the decision may entail risks as serious as death and may appear mistaken in the eyes of the medical profession or of the community. Regardless of the doctor's opinion, it is the patient who has the final say on whether to undergo the treatment."

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[769] Irvine JC, Osborne PH & Shariff MJ *Canadian Medical Law An introduction for Physicians and other Health Care Professionals* 4th Ed (2013) 677.
[770] Irvine JC, Osborne PH & Shariff MJ *Canadian Medical Law An introduction for Physicians and other Health Care Professionals* 4th Ed (2013) 677.
[771] Irvine JC, Osborne PH & Shariff MJ *Canadian Medical Law An introduction for Physicians and other Health Care Professionals* 4th Ed (2013) 678.
[772] *Malette v Shulman* et al 72 O.R. (2d) 417 [1990] O.J. No. 450. See Siebrasse N "Malette v Shulman: The Requirement of Consent in Medical Emergencies" (1989) 34 *McGill Law Journal* 1080-1098.

In practice Canadian medical law functions similarly to the leading American case law.[773] Therefore Canadian Medical Law often refers to American jurisprudence. As mentioned above living wills and proxy directives are valid under Canadian law. However, the scope of the Provincial statutes vary in the different Provinces.[774]

In Canadian common law any surgeries or medical procedures conducted without the patient's consent, would usually amount to battery.[775] In the *Malette v Shulman*[776] case an Ontario Court of Appeal case, a physician was held liable for battery as he administered a blood transfusion to a patient, who was a Jehovah's witness and who had a signed medical alert card which stated that "no blood or blood products be administered to me under any circumstances". The patient had been severely injured and unconscious. The physician was given knowledge of the medical alert card by a nurse, but made the decision to nevertheless go ahead and provide the blood transfusion. The court declared:

> "The right to determine what shall be done with one's own body is a fundamental right in our society. The patient has the freedom to exercise her right to refuse treatment and to accept the consequences of her decision. To deny individuals freedom of choice with respect to their health care can only lessen, and not enhance, the value of life."

The court concluded that the legal effect of the medical alert card was that of an unqualified anticipatory refusal of a specific type of treatment namely the use of blood products. The court stated:

> "At issue here is the freedom of the patient as an individual to exercise her right to refuse treatment and accept the consequences of her own decision. Competent adults … are generally at liberty to refuse medical treatment even at

[773] Irvine JC, Osborne PH & Shariff MJ *Canadian Medical Law An introduction for Physicians and other Health Care Professionals* 4th Ed (2013) 555.
[774] Jordaan L "The legal validity of an advance refusal of medical treatment in South African law (Part 2)" (2011) *De Jure* 265.
[775] Irvine JC, Osborne PH & Shariff MJ *Canadian Medical Law An introduction for Physicians and other Health Care Professionals* 4th Ed (2013) 21.
[776] *Malette v Shulman* et al 72 O.R. (2d) 417 [1990] O.J. No. 450.

the risk of death. The right to determine what shall be done with one's own body is a fundamental right in our society. The concepts inherent in this right are the bedrock upon which the principles of self-determination and individual autonomy are based".[777]

In *Malette v Schulman*[778] an instructional directive which was treatment-specific was thus judicially recognised.

The Ontario Court of Appeal in the *Fleming v Reid*[779] judgment remarked the following regarding the physician-doctor relationship:

"The right to determine what shall, or shall not, be done with one's own body, and to be free from non-consensual medical treatment, is a right deeply rooted in our common law. This right underlies the doctrine of informed consent. With very limited exceptions, every person's body is considered inviolate, and, accordingly, every competent adult has the right to be free from unwanted medical treatment. The fact that serious risks or consequences may result from a refusal of medical treatment does not vitiate the right of medical self-determination. The doctrine of informed consent ensures the freedom of individuals to make choices about their medical care. It is the patient, not the doctor, who ultimately must decide if treatment – any treatment – is to be administered.

A patient, in anticipation of circumstances wherein he or she may be unconscious or otherwise incapacitated and thus unable to contemporaneously express his or her wishes about a particular form of medical treatment, may specify in advance his or her refusal to consent to the proposed treatment. A doctor is not free to disregard such advance instructions, even in an emergency. The patient's right to forego treatment, in the absence of some overriding societal

[777] *Malette v Shulman* et al 72 O.R. (2d) 417 [1990] O.J. No. 450 at 336.
[778] *Malette v Shulman* et al 72 O.R. (2d) 417 [1990] O.J. No. 450.
[779] *Fleming v Reid* 4 O.R. (3d) 74 [1991] O.J. No. 1083 85-86.

interest, is paramount to the doctor's obligation to provide medical care. This right must be honoured, even though the treatment may be beneficial or necessary to preserve the patient's life or health, and regardless of how ill-advised the patient's decision may appear to others.[780]

These traditional common law principles extend to mentally competent patients in psychiatric facilities. They, like competent adults generally, are entitled to control the course of their medical treatment. Their right of self-determination is not forfeited when they enter a psychiatric facility. They may, if they wish, reject their doctor's psychiatric advice and refuse to take psychotropic drugs, just as patients suffering other forms of illness may reject their doctor's advice and refuse, for instance, to take insulin or undergo chemotherapy. The fact that these patients, whether voluntarily or involuntarily, are hospitalized in a mental institution in order to obtain care and treatment for a mental disorder does not necessarily render them incompetent to make psychiatric treatment decisions. They may be incapacitated for particular reasons but nonetheless be competent to decide upon their medical care. The Act presumes mental competency, and implicitly recognizes that a mentally ill person may retain the capacity to function competently in all or many areas of everyday life."[781]

The court in *Fleming v Reid*[782] said the following regarding advance instructions:

"A doctor is not free to disregard a patient's advance instructions any more than he would be free to disregard instructions given at the time of the emergency. The law does not prohibit a patient from withholding consent to emergency medical treatment, nor does the law prohibit a doctor from following his patient's instructions. While the law may disregard the absence of consent in limited emergency circumstances, it otherwise supports the right of competent adults to

[780] *Fleming v Reid* 4 O.R. (3d) 74 [1991] O.J. No. 1083 at 85-86. Also cited in *Carter v Canada (Attorney General)* 2012 BCSC 886.
[781] *Fleming v Reid* 4 O.R. (3d) 74 [1991] O.J. No. 1083 at 87.
[782] *Fleming v Reid* 4 O.R. (3d) 74 [1991] O.J. No. 1083.

make decisions concerning their own health care by imposing civil liability on those who perform medical treatment without consent."[783]

Irvine *et al* remark that "a medical alert card refusing blood is really no different from an instructional directive refusing mechanical ventilation or tube-feeding if the person winds up in a persistent vegetative state, or a direction by a patient in a cardiac care unit that he is not to be resuscitated in the event of a cardiac arrest". Irvine explains that the *Malette v Schulman*[784] case "sets a binding legal precedent in Ontario that caregivers are legally bound to honour an advance directive that specifies the refusal of particular treatment options. The *Malette v. Schulman* case is what lawyers refer to as persuasive legal precedent. In other words, although the ruling is not binding outside Ontario, it is likely that it would be followed in comparable cases throughout Canada (keeping in mind that the local jurisdiction may have also captured the right to refuse treatment in specific legislation)."[785]

In *Fleming v Reid*[786] the Public Trustee instituted legal action, on behalf of two mentally incompetent patients, who were involuntarily detained in a psychiatric facility, to enforce the patients' rights to refuse treatment, specifically the administration of neuroleptic drugs, because the patients at the time when they were mentally competent had expressed the wish not to receive those drugs, which carried significant and unpredictable side effects. The treating psychiatrist on the other hand deemed the drugs beneficial to their mental conditions. The Ontario Court of Appeal found that the provisions of the Ontario Mental Health Act[787] which granted the authority to physicians to override a competent patient's wishes in the interest of a patient's best interests unjustifiably infringed the right to security of the person guaranteed in section 7 of the Canadian Charter of Rights and Freedoms. The court stated that:

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[783] *Fleming v Reid* 4 O.R. (3d) 74 [1991] O.J. No. 1083.
[784] *Malette v Shulman* et al 72 O.R. (2d) 417 [1990] O.J. No. 450.
[785] Irvine JC, Osborne PH & Shariff MJ *Canadian Medical Law An introduction for Physicians and other Health Care Professionals* 4th Ed (2013) 678 711.
[786] *Fleming v Reid* 4 O.R. (3d) 74 [1991] O.J. No. 1083.
[787] Ss 35(2)(b)(ii) & 35a Mental Health Act, R.S.O 1980, c. 262.

> "A patient, in anticipation of circumstances wherein he or she may be unconscious or otherwise incapacitated and thus unable to contemporaneously express his or her wishes about a particular form of medical treatment, may specify in advance his or her refusal to consent to the proposed treatment. A doctor is not free to disregard such advance instructions, even in an emergency. The patient's right to forgo treatment, in the absence of some overriding societal interest, is paramount to the doctor's obligation to provide medical care. This right must be honoured, even though the treatment may be beneficial or necessary to preserve the patient's life or health, and regardless of how ill-advised the patient's decision may appear to others."

In *Nancy B v Hôtel Dieu de Québec*[788] the factual scenario went further than the mere refusal of medical treatment. In this case the 25-year old patient who suffered from Guillain Barré Syndrome, refused treatment and in addition requested that treatment that had been initiated be withdrawn. Guillain Barré syndrome is a neurological disorder which cannot be reversed and which led to the patient's complete and permanent paralysis, which left her dependent on mechanical ventilation. The plaintiff sought an injunction which would require the hospital to withdraw the respiratory support once the patient requests same. The hospital psychiatrist found the patient to be mentally competent and that her request was informed and given freely. The court summarised the patient's request as follows:

> "What Nancy B is seeking, relying on the principle of personal autonomy and her right to self-determination, is that the respiratory support treatment being given cease so that nature may take its course; that she be freed from slavery to a machine as her life depends on it. In order to do this, as she is unable to do it herself, she needs the help of a third person. Then, it is the disease which will take its natural course."[789]

[788] *Nancy B v Hôtel Dieu de Québec* (1992) 86 DLR (4th) 385 (Que S.C.).
[789] *Nancy B v Hôtel Dieu de Québec* (1992) 86 DLR (4th) 385 392.

The court reviewed the applicable common law and civil law of Québec regarding informed consent and concluded that:

> "The logical corollary of this doctrine of informed consent is that the patient generally has the right not to consent, that is the right to refuse treatment and to ask that it cease where it has already begun."[790]

The court then had to decide whether this right could be limited by criminal law. The court found that the Criminal Code[791] did not impede the withdrawal of the life-sustaining treatment. The court said that an individual would terminate Nancy B's respiratory support, would allow nature to take its course and would not be acting unlawfully and therefore granted the order to permit the patient's physician to terminate respiratory support on the patient's request.

In the *Rodriguez* decision the Supreme Court of Canada confirmed that patients have the right to refuse or discontinue treatment:

> "Canadian courts have recognized a common law right of patients to refuse consent to medical treatment, or to demand that treatment, once commenced, be withdrawn or discontinued. This right has been specifically recognized to exist even if the withdrawal from or refusal of treatment may result in death."[792]

In *Ciarlariello v Schacter*[793] the Supreme Court of Canada confirmed that the principles of individual freedom and self-determination which include the right to decide "what is to be done to one's own body" and the "right to be free from medical treatment to which the individual does not consent" which form part of individual autonomy are "fundamental to the common law" and the "basis for the requirement that "disclosure [must] be made to a patient".[794] The Supreme Court of Canada confirmed the above

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[790] *Nancy B v Hôtel Dieu de Québec* (1992) 86 DLR (4th) 385 390.
[791] Specifically Criminal Code ss 45, 216, 217 & 219.
[792] *Rodriguez v British Columbia (Attorney General)* [1993] 3 S.C.R. 519 598.
[793] *Ciarlariello v Schacter* [1993] 2 S.C.R 119.
[794] *Ciarlariello v Schacter* [1993] 2 S.C.R 119 at 135.

principles of informed consent in *AC v Manitoba* (*Director of Child and Family Services*).[795] The Supreme Court said that

> "…the legal environment for adults making medical treatment decisions is important because it demonstrates the tenacious relevance in our legal system of the principle that competent individuals are – and should be – free to make decisions about their bodily integrity."[796]
>
> "At common law, adults are presumptively entitled to direct the course of their own medical treatment and generally must give their 'informed consent' before treatment occurs, although this presumption of capacity can be rebutted by evidence to the contrary.[797] When competency is not in question, this right 'to decide one's own fate'[798] includes the unqualified right to refuse life-saving medical treatment."[799]

The common law principles can thus be summarised as follows. A competent adult as an autonomous informed patient has the right to consent to treatment and this right includes the right to withdraw consent to any life-sustaining treatment.[800] However in situations where patients are not mentally competent to convey their health care instructions contemporaneously, most provinces and territories have legislation that allows for the legal enforcement of advance directives. *Malette* and *Fleming* confirmed that an individual's instructions regarding future treatment will prevail in future when he or she becomes mentally incompetent. In the absence of legislation, the above common law position will govern.[801] In the *Conway v Jacques*[802] case the Ontario court found that if a patient is found to be incompetent and his or her treatment preferences are not known, the common law and the applicable statutory framework allows that medical decisions be made in the patient's best interests. The legislative framework that governs

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[795] *AC v Manitoba (Director of Child and Family Services)* 2009 SCC 30 at 39-45.
[796] *AC v Manitoba (Director of Child and Family Services)* 2009 SCC 30 at 39.
[797] See Ferguson L "The End of an Age: beyond Age Restrictions for Minors' Medical Treatment Decisions" Paper prepared for the Law Commission of Canada (29 October 2004) at 5.
[798] *Re T (adult refusal: medical treatment)* [1992] 4 All E.R. 649 at 661.
[799] *AC v Manitoba* (Director of Child and Family Services) 2009 SCC 30 paras 40.
[800] *Carter v Canada (Attorney General)* 2012 BCSC 886 at 220.
[801] *Carter v Canada (Attorney General)* 2012 BCSC 886 at 222.
[802] *Conway v Jacques* (2002) 214 D.L.R. (4th) 67 (Ont C.A).

living wills and advance directives and related end-of-life issues in Canada is summarised below.

4.5.3. Legislative Framework

4.5.3.1 Federal Legislation

4.5.3.1.1 The Canadian Constitution which contains the Charter of Rights and Freedoms

The Canadian Constitution which contains the Charter of Rights and Freedoms is Canada's supreme law. All legislation that is inconsistent with or contrary to the Canadian Charter of Rights and Freedoms is unconstitutional.[803] In the *Carter* decision for example the Supreme Court of Canada had to determine whether the criminal prohibition on assisted suicide violates the rights contained in section 7 of the *Charter,* namely the rights to life, liberty and security of the person[804] of competent adults who are suffering intolerably as a result of a grievous and irremediable medical condition, and to equal treatment by and under the law. See paragraph 4.5.5.1 below for a discussion on the *Carter* judgment.

4.5.3.1.2 The Criminal Code

In the *Carter v Canada* case the plaintiffs challenged the various sections of the Criminal Code which collectively prohibited physician assisted dying. These sections included section 14 which provides that no person is entitled to consent to have death inflicted on him or her, section 21 which *inter alia* makes it an offence for a person who acts or omits to do anything for purposes of aiding any person to commit an offence, section 22 which provides that a person who counsels another to be party to an offence,

[803] Irvine JC, Osborne PH & Shariff MJ *Canadian Medical Law An introduction for Physicians and other Health Care Professionals* 4th Ed (2013) 678 12.
[804] S 7 Canadian Charter of Rights and Freedoms.

can also be held liable for the offence, section 222 which defines the act of homicide, and section 241 which determines that everyone who either counsels a person to commit suicide, or aids or abets a person to commit suicide, whether suicide ensues or not, is guilty of an indictable offence.[805]

4.5.3.1.3 Bill C-14

After the *Carter*[806] judgment the federal government enacted Bill C-14.[807] On 17 June 2016 the Canadian federal government gave royal assent to the country's assisted dying law namely Bill C-14.[808] Bill C-14 amended the Criminal Code section, which stated the following with regard to consent to death:

> "No person is entitled to consent to have death inflicted on them, and such consent does not affect the criminal responsibility of any person who inflicts death on the person who gave consent".[809]

Bill C-14 amended the above section by adding an exemption for medical assistance in dying:

> "No medical practitioner or nurse practitioner commits culpable homicide if they provide a person with medical assistance in dying in accordance with section 241.2."[810]

Section 241 which criminalised the action of counselling, abetting or aiding suicide, was amended by providing an exemption for medical assistance in dying to medical practitioners, nurse practitioners, persons aiding the practitioners and the pharmacists who dispense the medicine, as follows:

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[805] See discussion on *Carter v Canada* 2015 SCC 5 in para 4.5.5.2
[806] *Carter v Canada* 2015 SCC 5.
[807] See discussion on *Carter v Canada* 2015 SCC 5 in para 4.5.5.2
[808] Statutes of Canada 2016 Chapter 3 "An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)" "Bill C-14" (Assented to 17 June 2016). (hereinafter "Bill C-14")
[809] S14 Criminal Code.
[810] S 227 (1).

"Counselling or aiding suicide

241 (1) Everyone is guilty of an indictable offence and liable to imprisonment for a term of not more than 14 years who, whether suicide ensues or not,

(a) counsels a person to die by suicide or abets a person in dying by suicide; or

(b) aids a person to die by suicide."

"Exemption for medical assistance in dying

(2) No medical practitioner or nurse practitioner commits an offence under paragraph (1)(b) if they provide a person with medical assistance in dying in accordance with section 241.2".

"Exemption for person aiding practitioner

(3) No person is a party to an offence under paragraph (1)(b) if they do anything for the purpose of aiding a medical practitioner or nurse practitioner to provide a person with medical assistance in dying in accordance with section 241.2".

"Exemption for pharmacist

(4) No pharmacist who dispenses a substance to a person other than a medical practitioner or nurse practitioner commits an offence under paragraph (1)(b) if the pharmacist dispenses the substance further to a prescription that is written by such a practitioner in providing medical assistance in dying in accordance with section 241.2."

There is also a general exemption for any person aiding the patient to self-administer the prescribed substance for medical assistance in dying. The section reads as follows:

"Exemption for person aiding patient

(5) No person commits an offence under paragraph (1)(b) if they do anything, at another person's explicit request, for the purpose of aiding that other person to self-administer a substance that has been prescribed for that other person as part of the provision of medical assistance in dying in accordance with section 241.2".[811]

[811] S 241(5) Bill C-14.

In terms of Bill C-14 two types of medical assistance in dying are allowed. The first situation is where a physician or nurse practitioner directly administers a substance to the person who had requested it and the person dies as a consequence.[812] The second form of medical assistance in dying is where a physician or nurse practitioner does not directly administer the lethal agent, but rather provides the substance to the patient or prescribes the substance for the patient to enable the patient to self-administer the substance to cause his or her own death.[813] As stated above any person aiding the patient to self-administer the substance is also exempt from criminal liability.

Bill C-14 further states that social workers, psychologists, psychiatrists, therapists, medical practitioners, nurse practitioners or other health care professionals do not commit an offence "if they provide information to a person on the lawful provision of medical assistance in dying".[814]

All persons who wish to receive medical assistance in dying must be evaluated by two independent health care professionals. These two health care professionals need to determine whether the person qualifies for medical assistance in dying.
Bill C-14 lists eligibility criteria that need to be met before a person may receive medical assistance in dying. These eligibility criteria are the following:

> "241.2 (1) A person may receive medical assistance in dying only if they meet all of the following criteria:
>
> (a) they are **eligible** — or, but for any applicable minimum period of residence or waiting period, would be eligible — for **health services** funded by a **government** in Canada;
>
> (b) they are at least **18 years of age** and capable of making decisions with respect to their health;
>
> (c) they have a **grievous and irremediable medical condition**;

[812] S 241.1(a) Bill C-14.
[813] S 241.1(b) Bill C-14.
[814] S 5(1) Bill C-14.

(d) they have made a **voluntary request** for medical assistance in dying that, in particular, was not made as a result of external pressure; and

(e) they give **informed consent** to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care."[815]

"Grievous and irremediable medical condition" is defined as follows:

"(2) A person has a grievous and irremediable medical condition only if they meet all of the following criteria:

(a) they have a serious and incurable illness, disease or disability;

(b) they are in an advanced state of irreversible decline in capability;

(c) that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; **and**

(d) their natural death has become **reasonably foreseeable**, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining."

In summary, to be eligible for medical assistance in dying, the individual must be 18 years of age or older and eligible for government-funded health care. The request for medical assistance in dying must be given on a voluntary basis and the individual must be capable of providing informed consent at the time the medical assistance in dying is provided. Furthermore, the individual must have a "grievous and irremediable medical condition" which entails the following: The individual must have a serious and incurable illness, disease or disability; the individual must be in an advanced state of irreversible decline in capability; the individual must endure physical and psychological suffering that is intolerable to him or her and cannot be relieved under acceptable conditions to the patient; the individual's death must be "reasonably foreseeable". The wording of Bill C-14 is much more restrictive with reference to the accessibility of assisted suicide than

[815] Own emphasis. Ss241.2 (1) (a) – (e) Bill C-14.

the Court's findings in the *Carter* judgment. In the *Carter* decision the Court said that physician assisted dying is to be available to any competent adult who consents to it and who has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances. The drafter of Bill C-14 took "grievous and irremediable medical condition" to be interpreted that the individual must be in an advanced state of irreversible decline and that the natural death must be "reasonably foreseeable". The vague term "reasonably foreseeable", which was not mentioned in the *Carter* judgment, but is contained in Bill C-14, has been critiqued by the legal and medical fraternity.[816]

Bill C-14 lists the following safeguards which a medical practitioner or nurse practitioner must meet before providing medical assistance in dying. Bill-14 states that the medical practitioner or nurse practitioner must be of the opinion that all the eligibility criteria were met and the person's request must be in writing and signed and dated before two independent witnesses who also signed and dated the request. The request can also be signed on behalf of the person requesting the assistance. In this regard Bill C-14 states that:

> "If the person requesting medical assistance in dying is unable to sign and date the request, another person — who is at least 18 years of age, who understands the nature of the request for medical assistance in dying and who does not know or believe that they are a beneficiary under the will of the person making the request, or a recipient, in any other way, of a financial or other material benefit resulting from that person's death — may do so in the person's presence, on the person's behalf and under the person's express direction."[817]

Bill C-14 explains what independent witnesses are:

> "Any person who is at least 18 years of age and who understands the nature of the request for medical assistance in dying may act as an independent witness, except if they

[816] See Downie J "Medical Assistance in dying: lessons for Australia from Canada" *QUT Law Review* 17 1 133-140.
[817] S 241.2(4) Bill C-14.

(a) know or believe that they are a beneficiary under the will of the person making the request, or a recipient, in any other way, of a financial or other material benefit resulting from that person's death;
(b) are an owner or operator of any health care facility at which the person making the request is being treated or any facility in which that person resides;
(c) are directly involved in providing health care services to the person making the request; or
(d) directly provide personal care to the person making the request."

The request can only be signed and dated after the person/patient had been informed by a medical practitioner or nurse practitioner that he or she has a grievous and irremediable medical condition. The medical practitioner or nurse practitioner must ensure that the person had been informed that he or she may withdraw his or her request for medical assistance in dying at any time and in any manner. Furthermore, another medical practitioner or nurse practitioner has to provide a written opinion confirming that the person meets all of the eligibility criteria. The medical practitioner and nurse practitioner must be satisfied that they and the other medical practitioner or nurse practitioner are independent. There must be at least 10 clear days between the day on which the request was signed by or on behalf of the person and the day on which the medical assistance in dying is provided or if they and the other medical practitioner or nurse practitioner are both of the opinion that the person's death, or the loss of their capacity to provide informed consent, is imminent a shorter period that the first medical practitioner or nurse practitioner may consider appropriate, in the circumstances can be applied. Immediately before providing the medical assistance in dying, the person must be given an opportunity to withdraw the request to ensure that the person gives express consent to receive medical assistance in dying. However, if the person has difficulty communicating, all the necessary measures to provide a reliable means by which the person may understand the information that is provided to them and communicate their decision, must be taken. Section 241.3 explains that when

the requirements[818] are knowingly failed by the medical practitioner or nurse practitioner, then he or she

"is guilty of an offence and is liable

(a) on conviction on indictment, to a term of imprisonment of not more than five years; or

(b) on summary conviction, to a term of imprisonment of not more than 18 months".

Bill C-14 states that "everyone commits an offence who commits forgery in relation to a request for medical assistance in dying".[819] Bill C-14 also regulates the destruction of documents relating to the medical assistance in dying request and stipulates the terms of imprisonment to fit the relevant crimes.

Bill C-14 was further made subject to an independent review relating to requests for medical assistance in dying made by mature minors, advance requests and request where mental illness is the sole underlying condition.[820]

On 11 September 2019 the Quebec Superior Court delivered a landmark judgment regarding the applicability criteria of Bill C-14.[821] The court found that the "reasonably foreseeable" criteria in federal law which entails that that a person's death must be reasonably foreseeable to qualify for medical assistance in dying was unreasonably broad and excluded the applicants Jean Truchon and Nicole Gladu who suffer from incurable and painful medical conditions, but who are not terminally ill. The court also struck down a clause in Quebec's Bill 52[822] which restricted medical assistance in dying to applicants who are at the "end of life". The judge afforded the applicants the right to

[818] The requirements as set out in paragraphs 241.2(3)(b) to (i) and subsection 241.2(8) Bill C-14.
[819] S 241.4 (1) Bill C-14.
[820] S9.1(1) & (2) Bill C-14.
[821] *Jean Truchon et Nicole Gladu v Procureur Général du Canada et Procureur Général du Québec et autres* Québec Cour Supérieure No 500-17-099119-177 (11 September 2019).
[822] Bill 52 An Act respecting end-of-life care, 2013.

request medical assistance in dying and gave the federal and Quebec governments six months to amend their laws.[823]

4.5.3.2 Provincial and Territorial Legislation

As described in paragraphs 4.5.1.1 and 4.5.1.2 most provinces and territories have legislation on advance directives. In the absence of suitable legislation for advance directives, the common law position as set out in 4.5.2 will apply. Examples of provincial and territorial legislation include: Newfoundland's Advance Health Care Directives Act,[824] Prince Edward Island's Consent to Treatment and Health Care Directives Act,[825] Manitoba's Health Care Directives Act,[826] Saskatchewan's Health Care Directives and Substitute Health Care Decision Makers Act,[827] Quebec's Civil Code,[828] Alberta's Personal Directives Act,[829] British Columbia's Health Care (Consent) and Care Facility (Admission) Act and Representation Agreement Act[830] and Ontario's Health Care Consent Act,[831] Advocacy Act[832] and Substitute Decisions Act[833]. A few jurisdictions do not have legislation on advance directives specifically, for example New Brunswick and Nunavut.[834] Quebec's government introduced An Act Respecting End-of-Life Care which allows for assisted dying.[835] This Act came into force in December 2015 and was one of the country's major developments in reforming the law on assisted suicide.[836] The Quebec Act defines end-of-life care as "palliative care provided to end-of-life

[823] See Ruf C "Dying with Dignity Canada urges lawmakers to accept Quebec ruling on assisted dying" 11 September 2019 <https://www.dyingwithdignity.ca/quebec_decision_2019> (accessed 11-09-2019).
[824] Advance Health Care Directives Act, 1995.
[825] Consent to Treatment and Health Care Directives Act, 1996.
[826] Health Care Directives Act, 1993.
[827] Health Care Directives and Substitute Health Care Decision Makers Act, 1997.
[828] Quebec Civil Code, 1991.
[829] Personal Directives Act, 1996.
[830] Health Care (Consent) and Care Facility (Admission) Act, 1993 and Representation Agreement Act, 1996.
[831] Health Care Consent Act, 1996.
[832] Advocacy Act, 1992.
[833] Substitute Decisions Act, 1992.
[834] Irvine JC, Osborne PH & Shariff MJ *Canadian Medical Law An introduction for Physicians and other Health Care Professionals* 4th Ed (2013) 720-721.
[835] Bill 52 An Act respecting end-of-life care, 2013.
[836] Downie J "Medical Assistance in dying: lessons for Australia from Canada" *QUT Law Review* 17 1 128.

patients and medical aid in dying".[837] "Medical aid in dying" is defined as "care consisting in the administration by a physician of medications or substances to an end-of-life patient, at the patient's request, in order to relieve their suffering by hastening death".[838] The Act allows for medical aid in dying if specific criteria and safeguards are met, such as that only physicians may provide the medical aid in dying,[839] it must be reported[840] and the patient must request the medical aid in dying themselves, in a free and informed manner.[841]

4.5.4 Drafting, Validity and Applicability of Living Wills and Advance Directives

As far as the drafting, validity and applicability of living wills and advance directives in Canada are concerned, the provincial and territorial legislation mentioned in paragraph 4.5.3.2 above must be consulted. In the absence of suitable legislation for advance directives, the common law position as set out in 4.5.2 will apply.

4.5.5. Specific Circumstances

The most important case law pertaining to specific circumstances in which advance directives could be helpful, are discussed below.

4.5.5.1 Withdrawal of Life Support: *Rasouli* Case

In the *Rasouli*[842] case conflict arose between health care professionals and the substitute decision maker. Rasouli, the patient, was in an unconscious state, having been kept alive on a ventilator for over three years, at Sunnybrook hospital. The doctors found that Rasouli was in a persistent vegetative state, all appropriate medical

[837] S 3(3) An Act Respecting End-of-Life Care RSQ c S-32.0001.
[838] S 3(6) An Act Respecting End-of-Life Care RSQ c S-32.0001.
[839] S 30 An Act Respecting End-of-Life Care RSQ c S-32.0001.
[840] Ss 8, 36 & 46 An Act Respecting End-of-Life Care RSQ c S-32.0001.
[841] S 26 An Act Respecting End-of-Life Care RSQ c S-32.0001.
[842] *Cuthbertson v Rasouli* 2013 SCC 53.

treatments had been exhausted and the doctors had no realistic hope for his meaningful medical recovery. They sought to remove his life support and provide palliative care until he passed away. In their opinion providing life support might have caused harm and would not have provided any medical benefit. However, Rasouli's wife and designated substitute decision maker, Mrs Salasel, said that if her husband were capable of making the choice himself, he would have opted to be kept alive with appropriate care in line with his Muslim religious beliefs, and did not provide the requisite consent to withdraw her husband's life support.

The case eventually reached the Supreme Court of Canada. The Supreme Court had to decide whether the substitute decision maker's consent was indeed needed before life support could be withdrawn. If that were the case, and the substitute decision maker refused consent to the withdrawal, the court was asked to determine how the substitute decision maker's decision could be challenged either before the Consent and Capacity Board in pursuit of Ontario's Act Health Care Consent Act[843], or in the courts in terms of the common law. The Supreme Court found that doctors must secure consent from a substitute decision maker before withdrawing life support. However, if health care professionals find that a patient's substitute decision maker is not acting according to his or her legal duties under the applicable law (Ontario's Health Care Consent Act[844]), then the health care professionals should apply to the Consent and Capacity Board to review the substitute decision maker's decision.

4.5.5.2 Physician Assisted Suicide

4.5.5.2.1 *Rodriguez v British Columbia (Attorney General)*

In the *Rodriguez*[845] case, the applicant Sue Rodriguez, a patient with amyotrophic lateral sclerosis (ALS), a degenerative neurological condition, challenged the prohibition

[843] Health Care Consent Act, 1996, S.O. 1996, c. 2, Sch. A.
[844] *Health Care Consent Act, 1996*, S.O. 1996, c. 2, Sch. A.
[845] *Rodriguez v British Columbia (Attorney General*) [1993] 3 S.C.R. 519.

against assisted suicide found in section 241(b) of the Criminal Code[846]. Her challenge which was bought under the Canadian Charter of Rights and Freedoms, and reached the Supreme Court, was unsuccessful.

4.5.5.2.2 *Carter v Canada*

The landmark *Carter v Canada*[847] judgment opens as follows:

> "It is a crime in Canada to assist another person in ending his own life. As a result, people who are grievously or irremediably ill cannot seek a physician's assistance in dying and may be condemned to a life of intolerable suffering. A person facing this prospect has two options: she can take her own life prematurely, often by violent or dangerous means, or she can suffer until she dies from natural causes. The choice is cruel".[848]

In the *Carter v Canada*[849] case, the plaintiffs were the family of Kay Carter, a woman with spinal stenosis, an extremely painful degenerative condition, who was accompanied by her family to obtain assisted dying in Switzerland, and Gloria Taylor, a woman who had amyotrophic lateral sclerosis (ALS) who wanted the option of an assisted death. The Supreme Court of Canada had to determine whether the criminal prohibition on assisted suicide violates the rights contained in section 7 of the *Charter,* namely the rights to life, liberty and security of the person[850] of competent adults who are suffering intolerably as a result of a grievous and irremediable medical condition, and to equal treatment by and under the law[851]. The court was thus requested to balance on the one hand the autonomy and dignity of a competent adult who seeks death in response to a grievous and irremediable medical condition, and on the other

[846] S241(b) Criminal Code RSC 1985 c C-46.
[847] *Carter v Canada* 2015 SCC 5.
[848] *Carter v Canada* 2015 SCC 5 par 1.
[849] *Carter v Canada* 2015 SCC 5.
[850] S 7 Canadian Charter of Rights and Freedoms.
[851] S 15 Canadian Charter of Rights and Freedoms.

hand the sanctity of life and the need to protect the vulnerable. Section 7 of the Charter reads as follows:

> "Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice".[852]

The Court found that sections 241(*b*) and 14 of the *Criminal Code*[853] unjustifiably infringe section 7 of the *Charter* and are of no force or effect to the extent that they prohibit physician assisted death for a competent adult person who firstly clearly consents to the termination of life and secondly has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition. In the Trial Court Smith, J defined "physician-assisted dying" and "physician-assisted death" as "generic terms that encompass physician-assisted suicide and voluntary euthanasia that is performed by a medical practitioner or a person acting under the direction of a medical practitioner".[854] The Supreme Court concluded that individuals who meet rigorous criteria should be able to avail themselves of assistance in dying.

4.6 Conclusions

In this chapter the applicable International Law and other international instruments relevant to the legal enforcement of living wills and advance directives were discussed. Legislation pertaining to living wills and advance directives in the Netherlands, England and Canada were analysed. Each country with its own particular social context and legal system presents with particular end-of-life legal challenges which continue to evolve with changes in society, changes to the *boni mores* of society and advancements in technology and developments in medical science. The Expert Panel of the Royal Society of Canada on End-of-Life Decision-Making made recommendations

[852] S 7 Canadian Charter of Rights and Freedoms.
[853] Criminal Code RSC 1985 c C-46.
[854] *Carter v Canada (Attorney General)* 2012 BCSC 886.

regarding the improvement of legal enforcement of advance directives in Canada in its report. It is clear that these are universal problems and could also have application in South Africa. The expert panel for example found that “The main problems with respect to advance directives and end-of-life care have less to do with the content of the law than with its implementation.”

The legal comparison has shown that in the chosen jurisdictions for legal comparison namely the Netherlands, England and Canada, different terminology and applicability criteria are utilised. The law is thus complicated and the implementation thereof even more so. The Expert Panel also notes that “very few Canadians have completed advance directives and very little advance care planning is done”. In South Africa where living wills and advance directives do not have clear legal status and legal enforcement frameworks and mechanisms, the legal uncertainty causes very few people to know about these documents and the benefits of such documents. The “clear evidence of communication failures between patients, family members and health care providers” is a universal problem. The report states that “End-of-life issues remain topics avoided in routine clinical care despite an abundance of literature indicating that it is a topic many patients and families want to discuss. This is a matter of concern partly because it reflects a failure to engage in autonomy-enhancing care but also because it may result in some individuals receiving care that they do not want and some scarce medical resources being wasted on unwanted care.” To combat these issues, the Expert Panel recommended the following:

> “1. More research should be funded and conducted into how best to facilitate the completion of valid and useful advance directives and to engage in advance care planning.
>
> 2. Better education of health care providers and the public should be provided. If the public understands how to complete advance directives and the benefits of doing so, the completion rates and the validity and utility of the completed advance directives may increase with corresponding benefits for both the individuals and the health care system. If health care providers develop

knowledge and skills with respect to communicating about end-of-life care and advance care planning, individuals' wishes may be more accessible to guide care.[855]

3. More resources should be directed to encouraging and facilitating discussions of advance directives and advance care planning. For example, such discussions could be billable to provincial health care plans and individuals particularly skilled in such conversations should be available to patients in health care institutions.

4. More effective administrative mechanisms should be developed to ensure that the results of discussions of advance directives and advance care planning are made evident in a variety of contexts of care. For example, it should be (but often is not) possible for an advance directive and advance care plan to follow an individual seamlessly from an acute care setting to a long term care facility and back again."[856]

The principles of improved research, education, more resources and more effective administration mechanisms to enhance the legal enforcement of living wills and advance directives can be applied to other countries such as South Africa where development of the law with reference to living wills and advance directives must still take place. The Netherlands, England and Canada have problems with the scope and applicability of these advance directives, living wills, advance requests, advance decisions, *wilsverklaringe*, *levenstestamente* and the like. Dying with Dignity Canada therefore differentiates between an advance directive and an advance request, specifically for medical assistance in dying. In Canada legal challenges are being brought to challenge the applicability of Bill C-14 such as the criteria of a "reasonably

[855] Schüklenk U, Van Delden JMM, Downie J, AMS Mclean, Upshur R and Weinstock D "End-of-Life Decision-Making in Canada: The Report by the Royal Society of Canada Expert Panel on End-of-Life Decision-Making" (2011) *Bioethics* 25 No SI 1-73 93.

[856] Schüklenk U, Van Delden JMM, Downie J, AMS Mclean, Upshur R and Weinstock D "End-of-Life Decision-Making in Canada: The Report by the Royal Society of Canada Expert Panel on End-of-Life Decision-Making" (2011) *Bioethics* 25 No SI 1-73 94.

foreseeable" death.[857] In the Netherlands the discussion surrounding cases of completed life and age restrictions for euthanasia are debated and legally challenged. In England the Parliament has recently debated assisted dying and more cases are brought to court to challenge the legal position. All these legal challenges will have an impact on the drafting and applicability and legal enforceability of living wills and advance directives in these countries.

The development of legal frameworks in the three countries discussed in this chapter can provide valuable guidelines for South Africa. The next chapter therefore utilises aspects of the legal frameworks discussed in this chapter to create a functional legal framework for the regulation and legal enforcement of living wills and advance directives in South Africa with reference to specific circumstances and the drafting of living wills or advance directives in the South African context.

[857] *AB v Canada (Attorney General)* 2017 ONSC 3759; *Lamb v Canada (Attorney General)* 2018 BCCA 266. *Jean Truchon et Nicole Gladu v Procureur Général du Canada et Procureur Général du Québec et autres* Québec Cour Supérieure No 500-17-099119-177 (11 September 2019).

CHAPTER 5:

THE DRAFTING OF LIVING WILLS AND THE CURRENT STATUS OF LEGAL ENFORCEABILITY AND APPLICABILITY OF LIVING WILLS IN SOUTH AFRICA AS THEY RELATE TO SPECIFIC CIRCUMSTANCES

Outline

5.1 Introduction

In chapter 3 the South African position on living wills and advance directives was discussed, and in chapter 4 an international legal comparison of living wills and advance directives in terms of International Law, the Netherlands, England and Canada, was conducted. Chapters 3 and 4 therefore set the scene for this chapter which provides general guidelines for a legislative framework for living wills in South Africa. The specific circumstances that a drafter/maker would need to consider when drafting a living will or advance directive are also discussed. Living wills and advance directives potentially have far-reaching quality of life and even quality of death consequences for an individual; therefore it is important to refer to varying circumstances which may be relevant to the individual requiring the enforcement of a living will. In this chapter the following specific circumstances will be discussed: emergency situations and do-not-resuscitate orders, permanent vegetative states, dementia, cessation of artificial hydration and feeding, pregnancy, euthanasia and assisted suicide, palliative care and pain relief and organ donation. Draft example clauses which can be used in living wills to convey instructions pertaining to these specific circumstances are provided. Draft examples of living will documents are also included. *Caveat*: these draft examples of possible living will clauses and documents are merely published as academic examples and should not be construed as legal advice. Living wills and advance directives should be drafted specifically to cater for an individual's circumstances and specific requirements and they should not be too broad in ambit or too vague. Therefore generic examples or illustrations of living will clauses, such as provided in this chapter, should not be used without the necessary adaptations, as well as medical and legal advice to ensure the legal validity and legal enforceability of the document. In this chapter relevant references will be made to other jurisdictions to help fill the South African legal lacunae with reference to living wills.

5.2 Legal Nature of Living Wills and Advance Directives

Living wills and proxy directives can be classified as types of advance directives.[858] Advance directives are unilateral legal acts. These legal acts are premised on the existence of a suspensive condition. When the suspensive condition comes into existence for example when the patient is no longer *compos mentis* and a medical situation as described in the advance directive arises, then the document will take effect. Medical personnel must adhere to the instructions contained in the document if the document is found to be legally enforceable. Should the instructions contained in the document be against the public interest, such document could be found to be legally unenforceable. The question arises of how one is to test for public interest in medical situations. What are ethically acceptable interventions? What is the nature of the doctor-patient relationship? If such a document is legally enforceable and the doctor refuses to treat the patient as stipulated in the document and continues to treat the patient as if no document was in existence, will the doctor be held criminally liable even if the outcome was in the best interests of the patient? If the doctor refuses to treat the patient as requested in the document, should the doctor be obliged to refer the patient to another doctor who would be willing to act in terms of the document?[859]

If a patient who requests the withdrawal or withholding of treatment is mentally competent at the time he or she makes the request, there should not be a problem with the instructions conveyed. Problems arise, however, where such requests are made on behalf of mentally incompetent patients who have expressed their wishes in an advanced directive such as a "living will", or where an authorised person seeks to act on behalf of the patient, for example in terms of an enduring power of attorney.[860] In such

[858] See para 1.1.2.
[859] In terms of the South African abortion legislation, a medical practitioner with a conscious objection to perform an abortion, must refer a patient to a medical practitioner who would be willing. The Choice on Termination of Pregnancy Act, 92 of 1996 is silent on the aspect of conscientious objection but it can be inferred from S15 of the Constitution, the right to freedom of religion, belief and opinion. C Ngwena "Conscientious objection and legal abortion in South Africa: delineating the parameters" (2003) *Journal for Juridical Science* 28(1) 1-18.
[860] McQuoid-Mason D "The legal status of the living will" 1993 *CME* 59.

cases, where there are conflicting views concerning the wishes of the patient or the best interests of the patient, the court may be approached for relief.[861] It is submitted that "living wills" should be recognised by medical practitioners where there is clear and convincing evidence that they reflect the current wishes of the mentally incompetent patient (for instance where the patient has a copy of the "will" on his or her person, or has lodged a copy with his or her doctor or lawyer and the doctor or lawyer will be able to testify to that effect).[862]

The South African National Health Act which "provides a framework for a uniform health system in South Africa based on the obligations imposed by the Constitution of the Republic of South Africa, 1996 and other laws on the national, provincial and local governments with regard to health-care services", endeavours to harmonise legislation governing health care services, the Constitution and professional ethical norms.[863] The National Health Act[864] provides a mechanism for patients who may become mentally incompetent during (or as a result of) a health service, to appoint proxies to make decisions on their behalf in advance.[865] The requirements are that the mandate must be in writing and that the patient must be legally and mentally competent at the time that he or she executes the mandate. These proxy mandates take precedence over the wishes of relatives or partners. These proxy mandates are binding (whether the patient is temporarily or permanently unable to give consent) unless of course a court orders otherwise.[866]

In this thesis the law of succession as it pertains to the validity and enforceability of testamentary wills is investigated, as well as the relevant provisions of the Wills Act, that

[861] See discussion of *Clarke v Hurst NO and others* 1992 4 SA 630 (D) in para 3.6.1.
[862] Strauss SA *Doctor, Patient and the Law* (2001) 344-345.
[863] McQuoid Mason DJ & Dada MA *A-Z of Nursing Law* (2011) 192.
[864] National Health Act, Act 61 of 2003.
[865] S 7(1)(a)(i) National Health Act, Act 61 of 2003. See para 3.3.1.
[866] S 7(1)(b) National Health Act, Act 61 of 2003.

might serve as guidelines to some of the legal enforceability, validity and drafting issues experienced in the field of living wills and advance directives.[867]

5.3 General Principles for Drafting Living Wills, Advance Directives and Durable Powers of Attorney

5.3.1 The Living Will and Advance Directive

In countries where living wills and advance directives are legally binding contracts, certain common features of the two documents can be extrapolated. These include the following:

- The right to include personal tailor-made instructions unique to the maker's specific medical situation and personal circumstances.
- In instances where the maker requests assisted suicide or euthanasia in jurisdictions and such requests are legally permissible, specific legal requirements must be met regarding the nature and course of the illness, before a request will be considered. Different legal requirements exist in different jurisdictions, for example some jurisdictions state that the death must be "reasonably foreseeable",[868] or the suffering must be at a certain level for example "hopeless" and "unbearable".[869] The South African Draft Bill on End of Life Decisions[870] refers to "unbearable and intractable" suffering. The National Health Amendment Bill, 2019 (Private Member's Bill) also refers to a "terminal and incurable" medical condition, "a permanent vegetative state" or a "completely

[867] See paras 5.3.3 - 5.3.6.
[868] According to the Statutes of Canada 2016 Chapter 3 "An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)" "Bill C-14" (Assented to 17 June 2016) (hereinafter "Bill C-14")). See discussion para 4.5.3.1.3.
[869] In terms S2 of the Dutch Termination of Life on Request and Assisted Suicide (Review Procedures) Act, 2001. See discussion in para 4.3.3.3.
[870] Draft Bill on End of Life Decisions contained in the South African Law Commission Report *Project 86 Euthanasia and the Artificial Preservation of Life* (1997). ("Draft Bill on End of Life Decisions").

and irreversibly unconscious" state that must exist before effect can be given to a living will document.[871]

- Many living will statutes determine that in situations where a doctor is not able to carry out the provisions of the living will or advance directive or if the doctor does not wish to follow the provisions of a valid living will, or advance directive, he or she should transfer the patient's care to a doctor who would be willing to honour the living will or advance directive. This should be done, provided of course that the living will must be legally enforceable in terms of the legal validity requirements and the provisions cannot be such that the maker's consent would amount to consent to an illegal action, which would remain illegal even when consent is present. The provision can also not be *contra bonos mores*.
- In jurisdictions where living wills and advance directives are legally enforced, doctors are often obligated by law to incorporate the patient's living will into the patient's medical record (provided of course that the doctor is aware of the existence of such a document).[872]
- In terms of validity requirements multiple witnesses, often two witnesses, are usually requested to sign the document immediately after the patient has signed the document in their presence.[873] When a patient executes his or her testamentary will, witnessing is also a requirement contained in the Wills Act[874], that needs to be complied with.
- Living wills and advance directive documents should always contain a provision releasing the doctor and health care facility from liability for following the instructions contained in the living will or advance directive. The main aim of a living will or advance directive is not and should never be to secure non-prosecution of a doctor, but rather to protect and safeguard the wishes and instructions of a patient. It is in the process of safeguarding the patient's

[871] Cl 7B(3)(a)(i)-(iii) National Health Amendment Bill, 2019 (Private Member's Bill).
[872] See par 5.3.4 on the discussion on safekeeping of living wills and access to medical records.
[873] See further discussion on validity requirements of living wills and advance directives in par 5.3.3.
[874] Wills Act, 7 of 1953.

autonomy by adhering to his or her wishes and instructions that the doctor may be released from liability.

It is vital that doctors are allowed the freedom to perform their duty of relieving pain and suffering. The Draft Bill on End of Life Decisions describes the permissible conduct of medical practitioners in relieving distress as follows:

> "Should it be clear to a medical practitioner or a nurse responsible for the treatment of a patient who has been diagnosed by a medical practitioner as suffering from a terminal illness that the dosage of medication that the patient is currently receiving is not adequately alleviating the patient's pain or distress, he or she shall:
>
> a) with the object to provide relief of severe pain or distress; and
> b) with no intention to kill
>
> increase the dosage of medication (whether analgesics or sedatives) to be given to the patient until relief is obtained, even if the secondary effect of this action may be to shorten the life of the patient".[875]

The Draft Bill on End of Life Decisions furthermore prescribes that the above conduct should be documented in writing. The relevant clause reads:

> "A medical practitioner or nurse who treats a patient as contemplated [in clause 4(1) above] shall record in writing his or her findings regarding the condition of the patient and his or her conduct in treating the patient, which record will be documented and filed in and become part of the medical record of the patient concerned."[876]

The legal provision regarding withdrawal or withholding of nutrition varies from jurisdiction to jurisdiction and can be seen as a form of passive euthanasia.[877] In South Africa withdrawal and withholding artificial nutrition and water is legally permissible and can therefore be requested in a living will or advance directive. In England it is not

[875] Cl 4(1) Draft Bill on End of Life Decisions.
[876] Cl 4(2) Draft Bill on End of Life Decisions. See discussion on medical records in para 5.3.2.
[877] *Clarke v Hurst NO and others* 1992 4 SA 630 (D).

legally permissible to request withdrawal or withholding of nutrition and hydration, as nutrition and hydration are seen as “basic care” and health care workers in England are compelled to provide basic care.

In other jurisdictions living wills are not effective/applicable/enforceable if the patient is pregnant as it amounts to a change in circumstances which the pregnant patient might not have foreseen before becoming pregnant.[878]

Some jurisdictions allow for a patient’s family to provide consent and oral declarations regarding the existence and the contents of a patient’s living will or living wishes if not in writing.[879] Even though the doctors will follow the family’s consent or the patient’s wishes as conveyed orally by the family members, written declarations/statements will always be easier to prove and verify. At this point in time in South Africa the emphasis is placed on consent received from close family members. Doctors prefer to request family members to consent, even if there is a living will in existence, as doctors are not certain what the legal effect of a living will would be.

There are currently many draft versions of advance directives, living wills and durable or enduring powers of attorney for health care which are all worded differently, in existence. The wording in these documents also depends on the unique medical and personal circumstances of the maker, the legal framework pertaining to these documents specific to the jurisdiction in which he or she resides and/or the jurisdiction in which he or she would like to have the document enforced, as well as the types of legally permissible actions that can be requested in specific jurisdictions. Specific wording must be used to describe different aspects of the maker’s health care instructions to be applied under the different specified circumstances.

[878] See further discussion in par 5.9.
[879] *Cruzan v Director Missouri Dept of Health* 497 US 261 (1990).

5.3.2 Durable Powers of Attorney for Health Care

As noted in paragraph 3.4 the South African common law provides that a power of attorney becomes invalid once the person who granted the power of attorney, becomes mentally incapacitated, in other words an enduring or durable power of attorney is not yet recognised under the South African law. However, McQuoid-Mason argues that section 7 of the National Health Act[880] provides a possible mechanism to overcome this common law position. In future, when the necessary legal recognition has been granted to enduring or durable powers of attorney, the advance directive should contain the following clauses:

- The identification of the person or persons appointed to act as the maker's legal representative or representatives if he or she should become incapacitated.
- The legal representative or representatives must be empowered to make all medical decisions on the maker's behalf.
- The durable power of attorney should include detailed instructions which the legal representative must follow in future, should the maker become incapacitated and unable to communicate his or her health care decisions.

Beauchamp and Childress discuss various implementation problems with decisions made by surrogate decision makers:

> "[I]ndividuals have difficulty making decisions and specifying guidelines that adequately anticipate the full range of medical situations that might occur. As a result, designating surrogate decision makers has become common. Living wills and DPSs protect the patient against what the patient regards as harmful outcomes and also may reduce stress for families and health professionals who fear making the wrong decision. However, these documents also generate practical and moral problems. First, relatively few compose them, and when they do, they often fail to leave sufficiently explicit instructions. Second, a designated decision maker might be unavailable when needed, might be incompetent to make good decisions for the patient, or might have a conflict of interest, for

[880] National Health Act, 61 of 2003.

example, because of a prospective inheritance or an improved position in a family-owned business. Third, some patients who change their preferences about treatment fail to change their directives, and a few, when legally incompetent, protest a surrogate's decision. Fourth, laws often severely restrict the use of advance directives. For example, advance directives have legal effect in some locations if and only if the patient is terminally ill and death is imminent. Decisions must be made, however, in some cases in which death is not imminent or the patient does not have a medical condition appropriately described as a terminal illness. Fifth, living wills provide no basis for health professionals to overturn a patient's instructions; yet prior decisions could turn out not to be in the patient's best medical interest, although the patient could not have reasonably anticipated the precise circumstances while competent. Surrogate decision makers also make decisions with which physicians sharply disagree, in some cases asking the physician to act against his or her conscience. Sixth, some patients do not have adequate understanding of the range of decisions a health professional or a surrogate might have to make and, even with an adequate understanding, cannot foresee clinical situations and possible future experiences. Vague language often permeates living wills, thus necessitating inference and discretion. Nonetheless, the advance directive is a promising and valid way for competent persons to exercise their autonomy. From the perspective of bio-medical ethics, adequate methods of implementation that follow the outlines of the procedures for informed consent … can overcome these primarily practical problems."[881]

If a maker signs a durable power of attorney which will specify which person will serve as his or her agent, it is important that the maker approaches the proposed health care proxy beforehand to request whether that person will be willing to act as a health care proxy for the maker. It is important to do so since the proxy assumes a serious responsibility when agreeing to convey the maker's instructions to his or her health care workers. It is important to note that the proxy designate will not be mandated to make decisions based on his or her own personal judgment and values. The proxy is in

[881] Beauchamp TL & Childress JF *Principles of Biomedical Ethics* (2009) 186-187.

essence responsible for serving as a conduit between the patient and the doctor. In terms of the conduit principle decisions are seen to flow through from the patient to the doctor and not from the proxy to the doctor.

It is important to note that the proxy is not financially responsible for the patient's care on the basis of his or her appointment and designation alone. There must be another agreement to that effect or a familial relationship between the patient and the proxy which creates the financial responsibility.

It is not advisable for the maker's doctor to serve as his or her proxy because a conflict of interest may arise between the doctor's role as healer and the patient's autonomous preferences. In many states in the USA a patient's doctor is prohibited from serving as a proxy. The SA Law Commission report is silent on this point. The National Health Amendment Bill, 2019 also does not refer to this point. It is submitted that the patient's doctor should not be appointed as the patient's proxy because the doctor can be placed in an ethically difficult position if he has to adhere to patient autonomy on the one hand, but on the other fulfil his paternalistic role in accordance with the best interests of the patient.

5.3.3 Validity of Living Wills, Advance Directives and Durable Powers of Attorney

The Draft Bill on End of Life Decisions describes the conditions for directives concerning the treatment of terminally ill persons in clause 6(1) as follows:

> "6 (1) Every person above the age of 18 years who is of sound mind shall be competent to issue a written directive declaring that if he or she should ever suffer from a terminal illness and would as a result be unable to make or communicate decisions concerning his or her medical treatment or its cessation, medical treatment should not be instituted or any medical treatment which he or she may receive should be discontinued and only palliative care should be administered.

(2) A person as contemplated in [sub-clause] (1) shall be competent to entrust any decision making regarding the treatment as contemplated in that sub[clause] or the cessation of such treatment to a competent agent by way of a written power of attorney, and such power of attorney shall take effect and remain in force if the principal becomes terminally ill and as a result is unable to make or communicate decisions concerning his or her medical treatment or the cessation thereof.

(3) A directive contemplated in [sub-clause] (1) and a power of attorney contemplated in [sub-clause] (2) and any amendment thereof, shall be signed by the person giving the directive or power of attorney in the presence of two competent witnesses who shall sign the document in the presence of the said person and in each other's presence.

(4) When a person who is under guardianship, or in respect of whom a curator of the person has been appointed, becomes terminally ill and no instructions as contemplated in [sub-clause] (1) or (2) regarding his medical treatment or the cessation thereof have been issued, the decision making regarding such treatment or the cessation thereof shall, in the absence of any court order or the provisions of any other Act, vest in such guardian or curator."

The Draft Bill on End of Life Decisions[882] describes the conduct of a medical practitioner in compliance with directives by or on behalf of terminally ill persons, as follows:

"7(1) No medical practitioner shall give effect to a directive regarding the refusal or cessation of medical treatment or the administering of palliative care which may contribute to the hastening of a patient's death, unless –

[882] Cl 7(1) Draft Bill on End of Life Decisions.

(a) the medical practitioner is satisfied that the patient concerned is suffering from a terminal illness and is therefore unable to make or communicate considered decisions concerning his or her medical treatment or the cessation thereof; and

(b) the condition of the patient concerned, as contemplated in paragraph (a), has been confirmed by at least one other medical practitioner who is not directly involved in the treatment of the patient concerned, but who is competent to express a professional opinion on the patient's condition because of his expert knowledge of the patient's illness and his or her examination of the patient concerned.

(2) Before a medical practitioner gives effect to a directive as contemplated in [sub-clause] (1) he shall satisfy himself, in so far as this is reasonably possible, of the authenticity of the directive and of the competency of the person issuing the directive.

(3) Before giving effect to a directive as contemplated in [sub-clause] (1), a medical practitioner shall inform the interested family members of the patient of his or her findings, that of the other medical practitioner contemplated in paragraph (b) of [sub-clause] (1), and of the existence and content of the directive of the patient concerned.

(4) If a medical practitioner is uncertain as to the authenticity as regards the directive or its legality, he shall treat the patient concerned in accordance with the provisions set out in [clause] 8 below.[883]

[883] Clause 8 describes the conduct of a medical practitioner in the absence of a directive.

(5) (a) A medical practitioner who gives effect to a directive as contemplated in [sub-clause] (1) shall record in writing his or her findings regarding the condition of the patient and the manner in which he or she implemented the directive.

(b) A medical practitioner as contemplated in paragraph (b) of [sub-clause] (1) shall record in writing his or her findings regarding the condition of the patient concerned.

(6) A directive concerning the refusal or cessation of medical treatment as contemplated in [sub-clause] (1) and (2) shall not be invalid and the withholding or cessation of medical treatment in accordance with such a directive, shall, in so far as it is performed in accordance with this Act, not be unlawful even though performance of the directive might hasten the moment of death of the patient concerned."

Clause 8 prescribes the conduct a medical practitioner should follow in the absence of a directive as follows:

"Conduct of a medical practitioner in the absence of a directive

8 (1) If the chief medical practitioner of a hospital, clinic or similar institution where a patient is being cared for is of the opinion that the patient is in a state of terminal illness as contemplated in this Act and for this reason unable to make or communicate decisions concerning his or her medical treatment or its cessation, and his opinion is confirmed in writing by at least one other medical practitioner who has not treated the person concerned as a patient, but who has examined him and who is competent to submit a professional opinion regarding the patient's condition on account of his expertise regarding the illness of the patient concerned, the first-mentioned medical practitioner may, in the absence of any directive as contemplated in [clause] 6(1) and (2) or a court order as contemplated in [clause] 9, grant written authorisation for the cessation of all further life-sustaining medical treatment and the administering of palliative care only.

(2) A medical practitioner as contemplated in [clause] (1) shall not act as contemplated in [sub-clause] (1) if such conduct would be contrary to the wishes of the family members or close family of the patient, unless authorised thereto by a court order.

(3) A medical practitioner as contemplated in [clause] (1) shall record in writing his findings regarding the patient's condition and any steps taken by him in respect thereof.

(4) The cessation of medical treatment as contemplated in [sub-clause] (1) shall not be unlawful merely because it contributes to causing the patient's death."

It is advisable to renew living wills, advance directives and durable powers of attorney periodically when the maker's personal circumstances change, for example where he or she is diagnosed with a life changing illness, or where an illness has progressed or improved, or when there is a new medical advancement which the maker wishes to include in his or her instructions. Even though periodic renewal is not a validity requirement, it is advisable. Updating the documents will ensure that the maker's most recent wishes and instructions are reflected. A correctly executed living will and advance directive will remain in force, unless the maker revokes it. The same methods of revocation of testamentary wills should be viewed as legally permissible methods of revoking living wills, advance directives and durable powers of attorney. Durable powers of attorney also last indefinitely, unless the person executing the document limits the time of efficacy.

In countries where living wills are governed by provincial or state-specific legislation for example the United States of America, some states explicitly allow for the honouring of a living will signed in another state, whereas others do not address that issue at all. It is therefore recommended that patients who live part time in two or more states sign separate living wills which will either be valid in each state or valid in both states. In Canada the provinces have differing provincial legislation regarding the legal enforcement of advance directives.

When a surrogate decision maker was not appointed in an advance directive, Beauchamp & Childress have devised a list of qualifications that these decision makers should have:

1. "Ability to make reasoned judgments (competence)"
2. "Adequate knowledge and information"
3. "Emotional stability"
4. "A commitment to the incompetent patient's interests, free of conflicts of interest and free of controlling influence by those who might not act in the patient's best interests".

According to Beauchamp and Childress four types of decision makers for incompetent patients have been identified where treatment decisions regarding the withholding or terminating of treatment have to be made for incompetent patients. These four categories are families, doctors and other health care professionals, institutional committees, and courts.[884]

If doctors do not agree with a surrogate's decision, they need to find an independent source to review the situation for example the hospital's ethics committee or the courts. Where a doctor or caregiver is asked to perform an act which he or she regards as "contraindicated, futile, or unconscionable", the doctor or caregiver is "not obligated to perform the act but may still be obligated to help the surrogate or patient make other arrangements for care".[885]

The researcher suggests that interested parties should be able to contest the validity of a living will in the same manner that testamentary wills can be challenged.[886] It should also be possible for the court to condone any non-compliance with formalities pertaining to the execution and amendment of living wills, where the real intention of the maker is

[884] Beauchamp TL & Childress JF *Principles of Biomedical Ethics* (2009) 187.
[885] Beauchamp TL & Childress JF *Principles of Biomedical Ethics* (2009) 189.
[886] S 2(3) of the Wills Act, 7 of 1953 provides the courts with the power to condone non-compliance in execution or amendments of testamentary wills.

clear.[887] The Wills Act can serve as a point of departure in these condonation applications.[888] However, due to the serious nature of living will documents where questions regarding the validity of a living will may arise which may lead to non-compliance and subsequent court applications, the consequences of the interim medical compliance or non-compliance of the provisions contained in the living will can be life-altering for the patient - either to the patient's benefit or detriment. For example in an emergency where a patient has a "do not resuscitate order" in his living will, and the validity of the living will is questioned, the medical personnel will have to take an urgent decision whether to comply with the provisions of the living will or not, and such a decision cannot be postponed until a court gives clarity on the matter.[889] The National Health Amendment Bill, 2019 specifically states that:

> "A living will does not preclude emergency care until a person's condition can be established and the applicability of a living will can be determined".[890]

Court applications for declaratory orders on the validity of living wills are therefore not always practical in all circumstances.

5.3.4 Safekeeping of Living Wills: Medical Records and Living Wills Register

The safekeeping and accessibility of living wills is a very important factor to ensure the legal enforcement of the instructions contained in these documents. If the documents are not readily available, they cannot be relied upon, and the makers' instructions cannot be acted upon. If a living will is not readily available, timeously verified and speedily enforced, patient autonomy will not be preserved.

The current South African draft legislation does not provide information on the safekeeping and accessibility of living wills. In fact, the Draft Bill on End of Life

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[887] See formalities discussed in paras 5.3.5 & 5.3.6; See *Thaker v Naran* 1993 (4) SA 665 regarding the presumption of compliance with formalities in testate succession.
[888] S 2(3) of the Wills Act 7 of 1953.
[889] See discussion on emergency situations and do not resuscitate orders in para 5.5.
[890] Cl 7B(9) National Health Amendment Bill, 2019.

Decisions does not contain any provisions or regulations on the safekeeping of advance directives, neither does the SA Law Commission Report elaborate on this point.[891]

The National Health Amendment Bill 2019, (Private Member's Bill)[892] is also silent on this point. The drafters of the Bill did not know how to regulate the safekeeping of living wills to ensure that they are timeously accessible and verified. It is glaringly obvious that the administrative burden of a living wills register and verification of the documents as well as the financial implications to create such a national database, was not on the minds of the drafters of the Bill. This can be deduced from the fact that in the "Memorandum on the Objects of the National Health Amendment Bill, 2019" in response to the question whether the Bill will create any financial implications for the state, "none" is replied. Furthermore, with regard to the question of "organizational and personnel implications", "none" is also indicated.

Some jurisdictions have registers for living wills. Worldwide pro-living will societies and organisations provide tips on safekeeping of living wills and tips on how to make the existence of your living will known to the public and medical personnel in an emergency situation, for example to carry a living will card in your purse or to wear a wristband (comparable to a medic alert bracelet).[893]

In South Africa there is currently no register for living wills. The erstwhile Living Will Society used to send out *pro forma* living will forms and keep record of members' living wills, but this society is no longer in existence.

It is the researcher's submission that patients' advance directives and living wills should be included in their medical records to ensure that they are readily available to improve the enforceability of these documents. Ideally, a national register or databases, to which

[891] SA Law Commission "Report on Euthanasia and the Artificial Preservation of Life" "Project 86" (November 1998).
[892] National Health Amendment Bill, 2019 (Private Member's Bill).
[893] See discussion on p 296 regarding the methods employed to convey instructions in organ donation situations.

all hospital and emergency care facilities should have access, must be created for the storage of these documents. A specific task team, or organisation must be appointed to create and update a living wills register and to provide information requested by emergency personnel and other health care providers such as the existence and content of a person's living will. It is advisable that the register must be catalogued according to a person's name. His or her identity number as well as an appropriate photo for identification purposes should be included.

However, since South Africa does not have a living wills register, it is advisable that the patient's doctor keeps a copy of his or her living will on file to form part of the patient's medical record. It should clearly state on the copy where the original can be found. The original should be kept in a safe place and should be accessible to family members. These family members should be made aware of its existence and location. It is not advisable to file the Living Will with a person's Testamentary Will as a Testamentary Will only comes into operation after a person has passed away.

At the end of the SA Law Commission's report a submission that was made by the Department of Health is noted. They submitted that "treatment refusal forms" should be developed for inclusion in patients' medical records when they are admitted to hospital and that it should be established at the time of a patient's admission to hospital whether he or she has a living will. The Department of Health stated that this practice will give certainty to health care personnel. The Living Will Society strongly supported this view. It was recommended that the American Self-Determination Act of 1990 which regulates "admittance and consent to treatment forms" should be studied so that similar regulations can be included in South Africa's draft bill. It was strongly suggested that all hospitals, nursing homes, hospices, frail care centres and other health care institutions should ask the following question on admission forms: "'Have you signed a Living Will or advance directive?' and if the answer is in the affirmative, regulations should instruct that the Living Will is kept in the patient's 'In-patient' File for the duration of his or her stay in the given health care institution. Members of the Living Will Society are advised

that when signing a hospital consent form, the words… 'subject to the directions as stated in my Living Will' should be written immediately before their signature."[894]

The problem that however arises is the question of to whom these medical records actually belong? In England medical records belong to the patient. In South Africa, the medical practices hold the records in safekeeping, but patients have the right to view them at any time. Since there is currently not a functioning register of advance directives and living wills in South Africa, the best solution is for the document to be included in the patient's medical records. However, a living will should always be readily available and if it forms part of the medical record, it cannot be accessed instantaneously and thus is not always readily available. It is therefore recommended that the patient must in addition to the original document, carry a copy of his advance directives or living will on his person especially when going to hospital or travelling. There can still, however, be problems with reference to the applicability of the living will document as same only comes into operation once the patient is no longer mentally competent and thus is unable to confirm his or her wishes contained in the documents. It is submitted that certain presumptions should be built into the South African law on living wills as is done in international jurisdictions and already exist in South Africa in terms of the law of testate succession.[895]

According to Britz health records or medical records are "permanent records and are generated as a result of patient care. They include manual (hand-written), electronic and digital records. Examples include but are not limited to: doctor's notes; discharge summaries; letters between doctors; completed forms; templates and reports; imaging records; typed summaries; test results such as reports and print-outs from monitoring

[894] SA Law Commission Report *Project 86 Euthanasia and the Artificial Preservation of Life* (November 1998) 187-188.
[895] See for example the presumption of capacity contained in the English Mental Capacity Act discussed in para 4.4.3. See S 4 Wills Act, 7 of 1953 regarding presumptions of testamentary capacity and the testator's free expression of wishes in testate succession.

equipment; audio-visual records including clinical photographs; videos and tape-recordings; clinical research forms; data regarding assessments; and certificates".[896]

According to McQuoid-Mason & Dada: "Medical or health records consist of information kept by health-care professionals, health-care centres, community health clinics or hospitals detailing what the health-care professionals or other bodies know about the health condition and history of patients. The information is usually about medical examinations, treatment or operations, and should be recorded at the time of the consultation or immediately afterwards."[897] The HPCSA defines a health record as "any relevant record made by a health care practitioner at the time of or subsequent to a consultation and / or examination or the application of health management" which can contain "the information about the health of an identifiable individual recorded by a health care professional, either personally or at his or her direction."

The National Health Act provides that persons in charge of health-care establishments must ensure that proper health records are kept and that such records are properly controlled in respect of disclosure to third parties.[898] The National Health Act states that it is a criminal offence to tamper with health records.[899] The National Health Act contains a framework for protecting patient records and confidentiality. The National Health Act states the following in Section 14 regarding confidentiality:

> "Confidentiality
> 14 (1) All information concerning a user, including information relating to his or her health status, treatment or stay in a health establishment, is confidential.
> (2) Subject to section 15, no person may disclose any information contemplated in (1) - unless

[896] Britz PM *Medical record keeping in South Africa: A medico-legal perspective* (2018) (MPhil University of Pretoria) 3.
[897] McQuoid-Mason DJ & Dada MA *The A-Z of Nursing Law* (2011) 169.
[898] Ss 13-15 National Health Act, 61 of 2003.
[899] S 17(2) National Health Act, 61 of 2003.

(a) the user consents to that disclosure in writing;

(b) a court order or any law requires that disclosure; or

(c) non-disclosure of the information represents a serious threat to public health."

Section 15 of the National Health Act refers to access to health records and states the following:

"Access to health records

15 (1) A health worker or any health care provider that has access to the health records of a user may disclose such personal information to any other person, healthcare provider or health establishment as is necessary for any legitimate purpose within the ordinary course and scope of his or her duties where such access or disclosure is in the interests of the user.

(2) For the purpose of this section, "personal information" means personal information as defined in section 1 of the Promotion of Access to Information Act, 2000 (Act No. 2 of 2000)".

The Act prescribes the instances where health care providers can access health records, as follows:

"16 (1) A health care provider may examine a user's health records for the purposes of-

(a) treatment with the authorisation of the user; and

(b) study, teaching or research with the authorisation of the user, head of the health establishment concerned and the relevant health research ethics committee.

(2) If the study, teaching or research contemplated in subsection (1)(b)

reflects or obtains no information as to the identity of the user concerned, it is not necessary to obtain the authorisations contemplated in that subsection".[900]

The National Health Act[901] also prescribes the manner in which health records must be protected namely:

"Protection of health records

17. (1) The person in charge of a health establishment in possession of a user's health records must set up control measures to prevent unauthorised access to those records and to the storage facility in which, or system by which, records are kept.

(2) Any person who -

(a) fails to perform a duty imposed on them in terms of subsection (1);

(b) falsifies any record by adding to or deleting or changing any information contained in that record;

(c) creates, changes or destroys a record without authority to do so;

(d) fails to create or change a record when properly required to do so;

(e) provides false information with the intent that it be included in a record;

(f) without authority, copies any part of a record;

(g) without authority, connects the personal identification elements of a user's record with any element of that record that concerns the user's condition, treatment or history;

(h) gains unauthorised access to a record or record-keepingsystem, Including intercepting information being transmitted from one person, or one part of a record-keeping system, to another;

(g) without authority, connects any part of a computer or other electronic system on which records are kept to-

(i) any other computer or other electronic system; or

[900] S16 National Health Act, 61 of 2003.
[901] S17 National Health Act, 61 of 2003.

(ii) any terminal or other installation connected to or forming part of any other computer or other electronic system; or

(j) without authority, modifies or impairs the operation of-

(i) any part of the operating system of a computer or other electronic system on which a user's records are kept; or

(ii) any part of the programme used to record, store, retrieve or display information on a computer or other electronic system on which a user's records are kept,

commits an offence and is liable on conviction to a fine or to imprisonment for a period not exceeding one year or to both a fine and such imprisonment".

If a living will or advance directive forms part of a patient's medical record, it would be important to build a clause into the document to state that information may be divulged by the health care team to the treating doctors or physicians.

The methods used in organ donation situations to advise medical care givers of a persons' organ donation instructions, could be employed to help to alert medical care givers to the existence of persons' living wills. In terms of the National Health Act[902] a person can record organ donation instructions in writing in a will or document signed by him or her and at least two competent witnesses, or in an oral statement, in the presence of at least two competent witnesses, stating the intention to "donate his or her body or any specified tissue thereof to be used after his or her death…".[903] The Organ Donor Foundation of South Africa for example keeps record of registered organ donors, and their next of kin.[904] South Africa does not have a consolidated National database of organ donors and/or awaiting recipients.[905] Each transplant hospital keeps its own register. It is also possible for organ donors to obtain an organ donor disc, bracelet or

[902] National Health Act, 61 of 2003.
[903] S 62 National Health Act, 61 of 2003. See Labuschagne D "An analysis of organ donation in South African with specific reference to organ procurement" LLM University of Pretoria (2013) 28.
[904] Organ Donor Foundation "Donor Database" <https://www.odf.org.za/what-we-do/donor-database.html> (accessed 1-09-2019).
[905] Slabbert M & Venter B "Organ Procurement in Israel: Lessons for South Africa" (Nov 2015) *SAJBL* 8 2 46.

necklace from Medic Alert and Elixir Medical Shields to indicate to medical personnel that the patient is an organ donor, should he or she be incapacitated and not able to convey organ donation instructions.[906] Organ donation badges and wallet cards also exist. In practice however patients' family members are approached for consent before organ harvesting can proceed. It is submitted that once living wills receive the requisite legal recognition in South Africa, the same methods of conveying organ donation instructions (documents, discs, badges, cards, bracelet, necklaces etc) could be employed to convey the existence and content of a patient's living will.

In the landmark *Jansen van Vuuren v Kruger*[907] decision a medical practitioner disclosed his patient's HIV status to other medical practitioner friends whilst playing a game of golf. The medical practitioner divulged the information even though the patient had explicitly requested the doctor to hold the information in confidence. The patient then instituted legal proceedings claiming that the medical practitioner owed him a duty of confidentiality in terms of their doctor-patient relationship which includes information regarding a patient's medical and physical condition. The patient argued that because his HIV status was divulged by the medical practitioner, he had suffered an invasion of privacy and that his personality rights have been injured. The medical practitioner averred in his defence that the disclosure had been made on a privileged occasion, that it constituted the truth and that it was made in the public interest, and that it was therefore objectively reasonable of him to disclose the information in the public interest in line with the *boni mores* of society. The medical practitioner contended that it was his social and moral duty to disclose the patient's HIV status as the other two health care practitioners knew the patient and would then be able to apply due diligence when treating the patient, to prevent the illness from spreading. The court found that the duty of medical practitioners to respect the confidentiality of their patients is both an ethical duty, and a legal duty recognised by South African common law.

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[906] Medic Alert on (021) 425 7328/ 0861 112 979 or Elixir Medical Shields on 0861 115 178 can be contacted for further information (verified as correct on 9/5/2018).

[907] *Jansen van Vuuren v Kruger* 1993 4 SA 842 (AD). Also see Van Wyk C "VIGS, vertroulikheid en plig om in te lig" (57) 1994 *THRHR* 141.

The *NM v Smith*[908] case confirmed this legal position. The facts of the case are as follows: the applicants claimed that their rights to privacy, dignity and psychological integrity had been violated as their names and HIV positive statuses had been disclosed, without their prior consent in Patricia de Lille's published biography. Ironically, the applicants' details had been published in a chapter on de Lille's campaign work to improve the rights of people living with HIV and AIDS. The applicants' details were relevant to the discussion of a clinical trial in which they were involved which was also the source of complaints and a further enquiry into whether de Lille behaviour was ethical. The Constitutional Court found that medical information is not only private and confidential in the hands of health care personnel and stated that the applicants continued to have a direct interest to control the information about themselves and for it to remain confidential. The court said even though the applicants had given their consent to partake in the clinical trial and the subsequent enquiry into De Lille, they had not given consent for their names to be published in a book which was circulated nationwide.

5.3.5 Revocation of Living Wills

The revocation of a living will, advance directive or durable power of attorney should be a simple process to ensure that patients reserve their decision making autonomy by allowing them to quickly revoke the document, should they change their minds.

5.3.5.1 The Wills Act and Common Law

It is the researcher's submission that the manners in which a testamentary will can be voided in terms of the law of succession should also apply to living wills. The Wills Act[909] does not regulate the revocation of a testamentary will. The legal rules on how a

[908] *NM v Smith* 2007 5 SA 250 (CC).
[909] Wills Act, 7 of 1953.

testamentary will can be revoked, are all derived from common law.[910] If a will is revoked by the testator before his or her death, it will lose its legal force.[911]

Although the oral revocation of a testamentary will is not permissible by law (nor does the court have the power to condone such oral revocation), it is submitted that since the enforcement or non-enforcement of a living will has serious life and death consequences, it must be possible for a patient to revoke it orally.[912]

5.3.5.2 Draft Legislation

The National Health Amendment Bill, 2019 states that a "durable power of attorney for health care" "may be revoked at any time by the maker thereof by-

(a) a signed and dated letter of revocation;
(b) physically destroying it and any copies thereof;
(c) an oral expression of his or her intent to revoke it; or
(d) means of a later executed durable power of attorney for health care which is materially different from the former document."[913]

The Bill also refers to a revocation of a living will and states that "a living will" "may be revoked at any time by the maker thereof by –

(a) a signed and dated letter of revocation;
(b) physically destroying it and any copies thereof;
(c) an oral expression of his or her intent to revoke it; or
(d) means of a later executed living will which is materially different from the former document."[914]

[910] See De Waal MJ & Schoeman-Malan MC *Law of Succession* (2015) 88.
[911] *Wood v Estate Fawcus* 1935 CPD 350 352; *Theart v Wolfgang* [2011] ZAWCHC 138.
[912] See Cl 7B(8)(c) National Health Amendment Bill, 2019 on the oral revocation of a living will & Cl 7A(6)(c) National Health Amendment Bill, 2019 on the oral revocation of an enduring power of attorney.
[913] Cl 7A(6)(a)-(d) National Health Amendment Bill, 2019 (Private Member's Bill).
[914] Cl 7B(8)(a)-(d) National Health Amendment Bill, 2019 (Private Member's Bill).

The South African Law Commission's Report on Euthanasia and the Artificial Preservation of Life does not contain information on the revocation of a living will and the Law Commission's Draft Bill on End of Life Decisions also does not contain any provisions regarding the revocation of a living will.[915]

A living will could thus be revoked if the maker's intention to revoke it, was present for example if the maker destroys the documents or writes the word void across it. A very low standard of proof should be employed to adduce the maker's actual intention to revoke a living willl – should there be any doubt raised, such as any oral expression or any action indicating an intention of revocation, this should suffice as a valid action of revocation. Thus a low standard of proof – not beyond reasonable doubt or on a balance of probabilities, should be employed and if any doubt as to the maker's intention of revocation, it should not be enforced as these documents have such far reaching quality of life and even death consequences.

5.3.5.3 The Effect of Revocation

Should a patient revoke his or her living will, it could be an indication that he or she wants life-sustaining therapies to be initiated or continued, should he or she become terminally ill or persistently vegetative. A patient is free to change his or her mind and the contents of the living will at any given time. It is possible to change the person to whom the patient initially gave the decision making authority. It is also possible to modify the specific health care instructions. A patient can also decide to execute a new advance directive. The new advance directive should state clearly that the document supersedes all previously executed directives.

[915] South African Law Commission "Euthanasia and the Artificial Preservation of Life" "Project 86" (1997).

5.3.6 The Drafting Process

5.3.6.1 Doctor's Involvement in Drafting a Living Will

In South Africa there is no legal requirement that a patient should consult a doctor before signing a living will or advance directive. Patients are however encouraged to discuss the contents of their proposed living wills or advance directives with their doctors. Consulting a medical doctor should help patients to obtain a better understanding of what they will be consenting to or refusing. It will also help the doctor to understand the patient's motivation and decisions. The doctor-patient relationship is thereby improved.

5.3.6.2 Mental Competence

A patient who wishes to exercise his or her right to consent, must have the decisional capacity to do so. Soundness of mind is important. King argues that patients have a strong and clear moral interest and legal right to act as the ultimate decision makers regarding their own medical care. King argues further that this interest extends to all decisions, including decisions viewed by others as wrong – if made by a person who has the ability to make autonomous decisions.[916]

Patients must understand the importance and implications of advance directives. The signing of a living will or advance directive must be done on a completely voluntary basis. A person may not be coerced into making the decision, the decision cannot be made frivolously and the patient must be mentally stable at the time of making the decision.[917]

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[916] King NMP *Making sense of advance directives* (1991) 4.
[917] Doukas DJ & Reichel W *Planning for uncertainty: A guide to Living Wills and other Advance Directives for Health Care* (1993) 65.

The Draft Bill on End of Life Decisions describes mental competence to refuse medical treatment as follows:

"Every person

a) above the age of 18 years and of sound mind, or
b) above the age of 14 years, of sound mind and assisted by his or her parents or guardian,

is competent to refuse any life-sustaining medical treatment or the continuation of such treatment with regard to any specific illness from which he or she may be suffering".[918]

The Draft Bill further states that where a person is refusing treatment as described above,[919] it "should be clear to the medical practitioner under whose treatment or care the person […] is, that such a person's refusal is based on free and considered exercise of his or her own free will, he or she shall give effect to such a person's refusal even though it may cause the death or the hastening of death of such a person".[920]

The Draft Bill emphasises the fact that a person who may have physical impairments to communicating, should not immediately be regarded as having mental incompetence. The Draft Bill reads "Care should be taken when taking a decision as to the competency of a person, that an individual who is not able to express him or herself verbally or adequately should not be classified as incompetent unless expert attempts have been made to communicate with that person whose responses may be by means of other than verbal".[921]

In South Africa where we have eleven official languages, the Draft Bill touches on the fact that communication can be hampered where the medical practitioner does not understand or share the first language of the patient. The Draft Bill states that: "Where a

[918] Cl 3(1) Draft Bill on End of Life Decisions.
[919] As described in S3(1) Draft Bill on End of Life Decisions.
[920] Cl 3(2) Draft Bill on End of Life Decisions.
[921] Cl 3(3) Draft Bill on End of Life Decisions.

medical practitioner as contemplated [in cl 3(2)] does not share or understand the first language of the patient, an interpreter fluent in the language used by the patient must be present in order to facilitate discussion when decisions regarding the treatment of the patient are made".[922]

In terms of the South African law of succession testamentary capacity includes an age requirement as well as specific wording on the nature and the extend of the capacity required and provides that the onus of proof regarding testamentary incapacity, rests on the person alleging same.[923] S 4 of the Wills Act[924] is worded as follows:

> "Every person of the age of sixteen years or more may make a will unless at the time of making the will he is mentally incapable of appreciating the nature and effect of his act, and the burden of proof that he was mentally incapable at the time shall rest on the person alleging the same".

This wording can inform future legislation on living wills.

5.3.6.3 Witnessing

The South African Law Commission Draft Bill on End of Life Decisions[925] defines a "competent witness" as follows:

> "a person of the age of 18 years or over who at the time he witnesses the directive or power of attorney is not incompetent to give evidence in a court of law and for whom the death of the maker of the directive or power of attorney holds no benefit".

"Court" is defined as a "provincial or local division of the High Court of South Africa within whose jurisdiction the matter falls".

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[922] Cl 3(4) Draft Bill on End of Life Decisions.
[923] S 4 Wills Act, 7 of 1953.
[924] Wills Act, 7 of 1953.
[925] Draft Bill on End of Life Decisions as contained in the South African Law Commission Report *Project 86 Euthanasia and the artificial preservation of life* (November 1998).

The National Health Amendment Bill, 2019 (Private Member's Bill) describes the witnessing of a durable power of attorney and living will. The Bill states that:

> "the durable power of attorney … and any amendment thereof, must be in writing and be signed by the maker thereof and two competent witnesses, in one another's presence: Provided that one of the witnesses is not the spouse or partner of the maker, or related to the maker by blood or adoption".[926]

In terms of the witnessing of a living will, the National Health Amendment Bill states that a "living will … and any amendment thereof, must be in writing and be signed by the maker thereof and two competent witnesses, in one another's presence: Provided that one of the witnesses is not the spouse or partner of the maker or related to the maker by blood or adoption."[927]

In terms of the Wills Act[928] which governs the law of testate succession in South Africa, the testator should sign his or her will in the presence of two competent witnesses who are present at the same time.[929] These two witnesses are required to sign the last page of the will in the presence of the testator and in the presence of one another. The witnesses can sign anywhere on the last page[930] and can also sign by initialling. "Sign" is defined as "making of initials and, only in the case of a testator, the making of a mark".[931] Section 1 of the Wills Act defines a "competent witness" as "a person of the age of fourteen years or over who at the time he witnesses a will is not incompetent to give evidence in a court of law". Section 2(1)(*a*) states that:

> "no will executed on or after the first day of January, 1954, shall be valid unless –
>
> i) the will is signed at the end thereof by the testator or by some other person in his presence and by his direction; and

[926] Cl 7A(3) National Health Amendment Bill, 2019 (Private Member's Bill).
[927] Cl 7B(4) National Health Amendment Bill, 2019 (Private Member's Bill).
[928] Wills Act, 7 of 1953.
[929] S 2(1)(*a*) Wills Act, 7 of 1953.
[930] *Liebenberg v The Master* 1992 (3) SA (57) D.
[931] S 1 Wills Act, 7 of 1953.

ii) such signature is made by the testator or by such other person or is acknowledged by the testator and, if made by such other person, also by such other person, in the presence of two or more competent witnesses present at the same time; and

iii) such witnesses attest and sign the will in the presence of the testator and of each other and, if the will is signed by such other person, in the presence also of such other person; and

iv) if the will consists of more than one page, each page other than the page on which it ends, is also signed by the testator or by such other person anywhere on the page."

If the testator signs the will by making a mark, or if another person signs the will on the direction of the testator and in the testator's presence, then a commissioner of oaths must be present at the singing of the will and must attach his certificate in accordance with the procedure laid out in the Act.[932] Where a maker is mentally competent but has a physical impairment in signing his or her living will or advance directive, this commissioner of oaths mechanism of the Wills Act could be a possible solution in terms of which the maker would then be able to sign in an alternative manner or by directing a person to sign on his or her behalf in his or her presence.

Witnesses serve the purpose of acknowledging that a testator has indeed signed the directive. Should future challenges on whether the document was executed knowingly and freely, arise, the witnesses would be able to attest to that. The witnesses do not require knowledge of the contents of the will[933] and the testator does not have to confirm the contents thereof before applying his signature.[934]

[932] S2(1)(*a*)(v)(*aa*)-(*bb*)Wills Act, 7 of 1953.
[933] De Waal MJ & Schoeman-Malan MC *Law of Succession* (2015) 52 fn 127; *Ex parte Suknanan* 1959 (2) SA 189 (D) 190-191; *Sterban v Dixon* 1968 (1) SA 322 (C) 325; *Mellvill v The Master* 1984 (3) SA 387.
[934] *Roux v Lombard* (1895) 9 EDC 201; *In re Estate of WR Shaw* (1905) 26 NLR 3; *King v Nel* 1922 CPD 520 in De Waal MJ & Schoeman-Malan MC *Law of Succession* (2015) 52.

Witnesses should be chosen carefully. Their appointment should not give rise to a conflict of interest. Therefore a witness should not be a relative, health care provider, or an heir of the patient.[935]

5.4 The Moment of Death

The moment of death is an important concept in law. In terms of medical care, it is important to determine when a person may be classified as dead, so that a medical practitioner may be entitled to disconnect a life-sustaining machine such as a heart lung machine or ventilator. Should the dying person be an organ donor, organ harvesting can commence once a person is declared deceased.

The National Health Act[936] has clarified the South African position on death by stating that "death" sets in when one has reached "brain death".[937] When a patient is declared brain dead, the decision should be made to stop any further medical interventions and to abort current treatment for example to remove the patient from the ventilator. Where a brain-dead patient is on a ventilator, he or she is already dead and therefore removing the ventilator would not amount to killing the patient.[938]

It is important that the maker of a living will realises what standard of death is used to determine the moment of death in the South African context. In the case of a patient who consents to organ donation, the timing of the patient's death is vital to allow for optimal organ harvesting, transportation and transplantation in the recipient.[939]

The Draft Bill on End of Life Decisions determines when a person should be considered dead for the purposes of the Draft Bill. Clause 2(1) states that: "For the purposes of this

[935] DJ Doukas & W Reichel *Planning for uncertainty: A guide to Living Wills and other Advance Directives for Health Care* (1993) 65. See Cl 7A(3) National Health Amendment Bill, 2019 (Private Member's Bill).
[936] National Health Act, 61 of 2003.
[937] S1 National Health Act, 61 of 2003.
[938] *S v Williams* 1986 (4) 1188 (A); McQuoid-Mason DJ & Dada MA *A-Z of Nursing Law* (2011) 39.
[939] See further discussion on organ donation in par 5.12.

[Draft Bill], a person is considered to be dead when two medical practitioners agree and confirm in writing that a person is clinically dead according to the following criteria of death, namely:

a) the irreversible absence of spontaneous respiratory and circulatory functions; or
b) the persistent clinical absence of brain-stem function.

Clause 2(2) explains further that "[s]hould a person be considered to be dead[940], the medical practitioner responsible for the treatment of such person may withdraw or order the withdrawal of all forms of treatment".[941]

Strauss explains that the "moment of death" "may also be of the utmost importance in the law of insurance. One thinks of the clause invariably inserted into the small print of life insurance policies, whereby the policy will become null and void if the insured person were to die in consequence of suicide, within two years after the policy has been issued".[942]

In terms of criminal law, the moment of death is an important factor in determining whether an accused committed murder or culpable homicide. Strauss explains that:

> "…the moment of death may be of vital concern to the criminal law when issues of liability for the alleged murder or culpable homicide must be solved. … Whose act was the true cause of the deceased's death? Was the deceased still alive when the second assailant joined in the assault? – in which case the latter may himself be guilty of murder, a capital offence, not merely of attempted murder if the deceased had already expired."[943]

Strauss also explains the situation often encountered in end of life decision making where a critically injured person is connected to life support such as a heart-lung machine at a hospital. However, if the person was assaulted prior to hospitalisation, the

[940] According to the provisions of cl 2(1) Draft Bill on End of life Decisions.
[941] Cl 2(2) Draft Bill on End of Life Decisions.
[942] Strauss SA *Doctor, patient and the law* (1991) 322.
[943] Strauss SA *Doctor, patient and the law* (1991) 322 as was held in *S v Thomo and Others* 1969 (1) SA 385 (A) 205.

question may arise as to who is causally responsible for the death of the victim/patient? Would it be the wrongdoer who assaulted the victim/patient or the doctor who switched off the machine? Strauss notes that the majority of theories on causation would judge the original actor/wrongdoer as causally responsible for the death of the patient/victim. Strauss explains that according to the narrow causation theory in law the doctor's act may in such a case as cited in the example be held to be *causa causans* of death.

In *S v Williams*[944] the accused was charged with murder. The accused raised the defence that the shot he had fired was not the cause of the deceased's death, because the victim was attached to a ventilator at a hospital and that when the respirator was disconnected it constituted an *actus novus interveniens.* The court refused to uphold the defence. Strauss explains that even on factual scenario such as in *S v Williams* where the original wrongdoer was found to have caused the victim's/patient's death, it might be possible for a doctor to be held responsible as causally co-responsible for the patient's death in terms of some theories of causation. The doctor's criminal liability will then depend *inter alia* on the other elements of murder or culpable homicide namely unlawfulness and fault.

In *R v Makali*[945] the court posed the question "whether the deceased would have died when he did but for the appellant's unlawful act. If this inquiry gives an affirmative answer, the appellant is responsible for the death because he caused it to take place when it did, that is to say because he hastened it. Strauss refers to Russel who said that "the person wounded does not die simply *ex visitatione Dei*, but his death is hastened by the hurt which he received", and continues to explain that:

> "Death is caused by some other intervening human action, either the original wounding by the assailant, or the medical act subsequently performed. Judicially, the hastening of death may be tantamount to causing of death. According to the

[944] *S v Williams* 1986 (4) SA 1188 (A). Compare English cases *R v Malcherek and Steel* [1981] 2 All ER 422 and *Mail Newspapers plc v Express Newspapers plc* [1987] FSR 90.
[945] *R v Makali* 1950 (1) SA 340 (N).

theory of *conditio sine qua non* the hastening of death will invariably amount to the causing of death."[946]

Strauss has an interesting comment regarding the theory of *conditio sine qua non*: "According to the theory of *conditio sine qua non*, the hastening of death will invariably amount to the causing of death. In considering the question of unlawfulness in criminal law and the law of delict, the question arises of when the doctor will be entitled to switch off the resuscitation apparatus. Can we as lawyers give a conclusive answer to that? I am doubtful. In my opinion the best we can do is to indicate a method which might be employed in trying to find an answer."[947]

5.5 Emergency Situations and Do Not Resuscitate Orders

A common critique of living wills and advance directives is that these documents are often not physically available in emergency situations. Personnel attending to emergencies often are not aware of the existence of these documents as patients may not be in a position to convey its existence and location. If a patient was indeed *compos mentis* enough to convey such instructions, it would not have been necessary for an actual document of a living will or advance directive, as the patient would have been able to convey the instructions contained in the living will or advance directive him or herself for example orally. Oral instructions given by a mentally competent patient always supersede written instructions. It follows that if living wills and advance directives are not readily available in a medical emergency, they cannot be of any force or effect in that specific situation. Family members who are aware of the existence of a patient's living will or the location thereof, will often only bring it forth when they reach the hospital and that could be after emergency treatment has been initiated.

A further problem with living wills and advance directives in medical emergency situations is that often they are not applicable to the specific situation the patient finds

[946] *Russel on crime* 9th ed 381 in Strauss SA *Doctor, patient and the law* (1991) 323.
[947] Strauss SA *Doctor, patient and the law* (1991) 323.

him or herself in. The drafting of the living will and advance directive is therefore very important. It should not be too broad which will result in it not being applicable to the specific scenario, but it also should not be too narrow which will have the unintended result of not being applicable in the necessary situations.

Some medical personnel have the perception that living wills amount to mere do-not-resuscitate orders and might not act on alternative provisions in the document.[948] It is possible to have provisions contrary to do not resuscitate (DNR orders) or do not attempt resuscitation orders (DNAR orders) in a living will. A patient can for example request that resuscitation should be attempted and other life-sustaining treatment should be initiated in certain circumstances.

The subject of emergency medical treatment was historically ruled by common law.[949] However the Constitution of South Africa clearly states that: "No one may be refused emergency medical treatment".[950] The National Health Act states that "[a] health care provider, health worker or health establishment may not refuse a person emergency medical treatment".[951]

In terms of the National Health Act patients may not be treated without their informed consent, unless any delay in the provision of the health care service might result in their death or irreversible damage to their health, and they have not expressly, impliedly or by conduct refused that service. In such cases after the health care service has been provided, patients must be informed about their health status and the diagnosis, and the treatment options and their benefits, risks, costs and consequences.[952] Such patients

[948] Mirarchi FL "Does a living will equal a DNR? Are living wills compromising patient safety?" (2007) Journal of Emergency Medicine 33 3 303.
[949] Strauss SA *Doctor, patient and the law* (1991) 89.
[950] Section 27(3) Constitution of the Republic of South Africa, 1996.
[951] S 5 National Health Act, 61 of 2003.
[952] S 9 National Health Act, 61 of 2003.

must also be told about their right to refuse further treatment, and the implications, risks and obligations of such refusal.[953]

In the *Soobramoney* case the court said that: "The words "emergency medical treatment" may possibly be open to a broad construction which would include ongoing treatment of chronic illnesses for the purpose of prolonging life. But this is not their ordinary meaning, and if this had been the purpose which section 27(3) was intended to serve, one would have expected that to have been expressed in positive and specific terms".[954]

The common law grounds of justification for treatment in an emergency are "unauthorised administration" and "necessity".[955] The basis for medical treatment is usually informed consent.[956] However, Strauss explains that in any emergency, the will of the patient who is capable of expressing his will in a rational manner, must be respected. It is however possible to provide treatment against a patient's will in a legally permissible manner, but very limited situations exist in which that would be possible. Strauss explains that a legal ground for justification of providing treatment against a patient's will, would be in situations where the common law defence of necessity (*noodtoestand*) would be applicable. An example of necessity would be to treat a patient with the intent to protect social interest against a person's will, for example where the patient is suffering from an infectious disease and must be treated to prevent the disease from spreading. Another example Strauss provides is that doctors may in necessity vaccinate healthy persons against their will, to prevent the outbreak and spread of dangerous diseases in the community (statutorily compulsory immunisation).[957]

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[953] S 8(3) read with s 6(1)(d) National Health Act, 61 of 2003.
[954] *Soobramoney v Minister of Health, KwaZulu-Natal* 1998 (1) SA 765 (CC) 13. See case discussion in paragraph 2.3.8.
[955] See discussion in Carstens PA & Pearmain D *Foundational Principles of SA Medical Law* (2007) 907-917.
[956] See Chapter 3 para 3.4 for discussion on informed consent.
[957] Strauss SA *Doctor, patient and the law* (1991) 91.

The defence of necessity applies where a person acts in defence of his or her or somebody else's legally recognised interest (e.g. life, bodily integrity, property) which is threatened with immediate harm.[958]

Strauss distinguished the applicability of the ground of justification of necessity in a situation where a patient does not want treatment, but treatment may be in the interest of society and therefore takes place and the situation in which the necessity ground of justification can also applied where the doctor does not inform the patient fully of his medical condition, and therefore does not obtain true informed consent before treatment commences for example in cancer treatment cases because Strauss says if the doctor were not to refrain from informing the patient in good faith regarding the nature and seriousness of the disease it "may have the effect that the patient becomes depressed and desperate to such an extent that he refuses further medical treatment".[959] This is also known as the principle of therapeutic privilege.

It is important to note that all patients, including those who reject life support, should still receive appropriate medical care to preserve their dignity and minimise suffering. Where a mentally competent patient has not expressed unwillingness to undergo treatment but is merely unable to give consent on account of shock or unconsciousness, emergency medical treatment presents few legal problems. In these cases the doctor, nurse, paramedic or layman can rely on the common law doctrine of *negotiorum gestio* (unauthorised administration) to justify his actions.[960]

Strauss explains that the doctrine of unauthorised administration is capable of application not only to proprietary interests but also to personality interests. Strauss cites an example where it can be invoked in an emergency operation upon a non-consenting patient. After the surgery has commenced and patient under general anaesthetic, a serious condition is discovered which would medically warrant an

[958] McQuoid-Mason & Dada *A-Z of Nursing Law* 193.
[959] Strauss SA *Doctor, patient and the law* (1991) 92.
[960] Strauss SA *Doctor, patient and the law* (1991) 92.

immediate extension of the operation to endeavour to remedy the condition discovered, although such an extension was not contemplated by the parties.[961]

Strauss summarises the doctrine in relation to medical treatment as follows:[962]
In the first place there must be a real state of emergency. Strauss explains that there must be some event, natural disaster, accident or disease where the patient is confronted by a real possibility of death or serious bodily harm or deterioration of health. The danger must be such that immediate action is necessary to save the life or health of the patient. If a delay would not aggravate the patient's condition, his consent must first be obtained, at any rate where drastic surgery is envisaged. In *Esterhuizen v Administrator Transvaal*[963] a patient was subjected to deep x-ray therapy without granting the necessary consent. The defendant contended inter alia that because the patient's life expectancy had only been one year, it was a matter of life and death. The court held that there had been enough time to approach the patient's guardian for consent.

Secondly the patient must be unaware of the fact that he is medically treated, or must at least be incapable of properly appreciating the situation for example where the patient is unconscious, delirious or comatose. Total unconsciousness is not necessary. The patient's condition may be so that he is aware of the injury, but on account of the injury or shock, he is "incapable of properly appreciating the situation and of rationally considering the treatment proposed and giving meaningful consent".

Thirdly the treatment must not be against the will of the patient. According to our common law unauthorised administration/treatment is considered a so-called quasi contract and is based on the presumption that the person whose interests are protected, would have given consent to the rescue because it is in his interest. However an adult person of sane mind is considered to be the best judge of his own interests. Where

[961] Strauss SA *Doctor, patient and the law* (1991) 92.
[962] Strauss SA *Doctor, patient and* the law (1991) 93.
[963] *Esterhuizen v Administrator Transvaal* 1957 (3) SA 710 (T).

therefore the person concerned has imposed a prohibition upon the rescue action, the rescuer cannot rely on unauthorised administration as a defence.[964] The fact that the patient's condition is critical in itself will not justify medical treatment against his will, where he expressly in full possession of faculties of mind forbade treatment or a specific form of treatment. In *Phillips v De Klerk* 1983 the court recognised the right of a person who was severely injured in a road accident to refuse a blood transfusion on religious grounds.[965]

Strauss states that relatives of an injured person who himself would have been able to give consent had he been conscious, will not be entitled to place a prohibition on medical treatment.[966] In the case of a mentally ill person or juvenile below the age of 18, a prohibition imposed by a person lawfully entitled to give consent to medical treatment, must be respected, provided – so it is submitted – the prohibition does not go against what is objectively in the interest of the patient. Strauss says: "It is difficult to conceive on what legal ground the curator of a mental patient, or the guardian of a minor, may in an emergency situation dictate to a qualified medical practitioner, nurse, etc, to refrain from treatment which would manifestly be in the interest of the patient."[967]

The National Health Amendment Bill, 2019 (Private Member's Bill) states that a "living will" "does not preclude emergency care until a person's condition can be established and the applicability of a living will can be determined".[968] The Bill does however fail to mention what the status of a durable power of attorney will be in an emergency situation, when the document is not readily available or when the appointed agent cannot be timeously probed for instructions. Surely the existence or purported existence of a durable power of attorney when the agent is not readily available, cannot override

[964] Strauss SA *Doctor, patient and the law* (1991) 95.
[965] *Phillips v De Klerk* 1983 (unreported) as discussed in SA Strauss *Doctor, patient and the law* (1991) 94.
[966] Strauss SA *Doctor, patient and the law* (1991) 94.
[967] Strauss SA *Doctor, patient and the law* (1991) 95.
[968] Cl 7A(9) National Health Amendment Bill, 2019 (Private Member's Bill).

emergency care until the applicability and validity of the appointment and instructions from the agent can be obtained.

The ethical question regarding futile treatment of a patient is also an important factor to consider carefully. The availability of ever developing technology and advanced procedures and interventions, does not mean that any and/or all available interventions will be appropriate to each patient in each case. As required by medical ethics the practitioner should ensure that the patient and family members are fully informed regarding the treatment, the benefit and the burden thereof (beneficence, non-maleficence and informed consent). It is also important to discuss the likelihood of improvement in quality of life (informed consent regarding the benefit of the intervention). The doctor and family should ultimately respect and support the patient's decision.

The question arises: when is there a duty to rescue in emergency situations? Strauss states that in principle there is no legal duty upon a person to rescue another even if it could be expected of him on moral grounds to act positively to prevent damage.[969] A duty to come to the rescue might result from contract, for example, an ambulance driver or paramedic, or from statute, for example, where a duty is imposed on doctors, dentists and nurses who attend to a child, who has apparently been ill-treated or abused, to notify the Regional Director of Health and Welfare. The scope of duty to rescue is thus primarily determined by terms of contract or provisions of statute.

A duty to rescue by means of medical treatment will not arise where there is a danger for the would-be rescuer.[970] Strauss describes the situation where a doctor or paramedic may save the life of someone who apparently suffered a heart attack, by way of mouth-to-mouth resuscitation if the doctor has reason to believe that the person was suffering from aids. Slight as the risk of contracting HIV may be in performing the

[969] *Min of Police v Ewels* 1975 (3) SA 590 (A) 596H. SA Strauss *Doctor, patient and the law* (1991) 89.
[970] Strauss SA *Doctor, patient and the law* (1991) 91.

procedure, it is nevertheless conceivable that the juristic convictions of society would require the doctor to knowingly expose himself to that risk.

Strauss emphasises that when the doctrine of unauthorised administration is applied to the context of medical treatment, there is a duty placed on the rescuer to complete what he has commenced. Once the rescuer has taken it upon himself to care for the interests of the patient, he cannot simply abandon his task. Strauss emphasises that in instances where the rescuer fails to complete his self-imposed task in caring for the patient and the patient concerned suffers damage, the rescuer may be held legally liable. [971]

Medical treatment must be in the best interests of the patient. The duty of care expected from a rescuer is to exercise "reasonable care" when embarking on the rescue act. Where a doctor administers treatment, the doctor must apply the degree and skill which the "average, reasonable doctor would display in the same circumstances." Likewise the action of a nurse or paramedic will be judged in the light of the degree of skill expected from the average professional person in this field.[972] Strauss states that: "Depending on the severity of the injury and the availability of better qualified professionals, a doctor, nurse or paramedic may in case of dire emergency – where the patient is at death's door – attempt measures which go far beyond his or her training, competency or experience."[973]

"Modern technology has provided the rescuer with a vast array of technical aids, in particular medical equipment, to use in the treatment of casualty victims. Failure to use these aids may in circumstances be judged to constitute negligence. It may be stated as principle that the more sophisticated and available these aids are in a given situation, the more likely it is that failure to use them, or to utilise them fully, may be ruled legally blameworthy in the absence of an explanation for such non-use". [974]

[971] Strauss SA *Doctor, patient and the law* (1991) 95.
[972] Strauss SA *Doctor, patient and the law* (1991) 95 - 96.
[973] Strauss SA *Doctor, patient and the law* (1991) 96.
[974] Strauss SA *Doctor, patient and the law* (1991) 96.

In cases of extreme emergency even unqualified medical laymen may render aid to the injured and cannot be judged by the standards pertaining to any branch of the medical profession. "If a man has been critically injured and lies bleeding to death next to the roadside, the lay Samaritan who attends to the victim, may render such assistance as reasonable in the circumstances, even if it is to no avail. The court will not adopt the attitude of an armchair critic who is wise after the event, but will apply the standard of the reasonable man".[975] Strauss emphasises that it would be held unreasonable for a layman to treat a critically injured person if expert medical aid is immediately available. In practical terms when someone happens to arrive on the scene of a disaster where people are critically injured, it would be unwise for him to administer well-intended but unskilful first-aid unless he has first ascertained whether a doctor or another professional with expert medical knowledge is available on the spot or within easy reach.[976]

Carstens and Pearmain provide the following example of a "Do not resuscitate" order:[977]

"EXAMPLE ONLY"*

DO NOT RESUSCITATE

[Date]

[Patient's Name]

Based on medical ethics and acceptable standards of medical care, patient will not have a reasonable chance of benefiting from treatment. Given patient's [describe condition], I hereby direct any medical personnel, commencing on the effective date noted above, to

[975] Strauss SA *Doctor, patient and the law* (1991) 96.
[976] Strauss SA *Doctor, patient and the law* (1991) 96.
[977] Carstens PA & Pearmain D *Foundational Principles of SA Medical Law* (2007) "Annexure O" Source: American Medical Association *Medicolegal Forms with Legal Analysis* (1991).

withhold cardiopulmonary resuscitation from the patient in the event of the patient's cardiac or respiratory arrest. I further direct such personnel to provide to the patient other medical interventions, such as intravenous fluids, oxygen, or other therapies deemed necessary to provide comfort care or to alleviate pain.

……...

Physician's printed name

……

Physician's signature

……

Telephone Pager

……...

Signature of Patient or Health Care Surrogate Date

Note: A version of the information in this form should also be noted in the patient's chart.

* NOTE DISCLAIMER AT THE END OF THE INDEX[978]

5.6 Persistent Vegetative States

The court in *Clarke v Hurst*[979] described a persistent vegetative state as follows:

> "The term "persistent vegetative state" seems to have been created by Dr Fred Plum, professor and chairman of the Department of Neurology at Cornell University and a world renowned neurologist. It describes a neurological

[978] Disclaimer: "The authors and publishers of this book wish to emphasise the fact that the foregoing annexures (as contained on the CD-Rom), specifically the examples of various forms and precedents are solely offered as practical generic examples/illustrations of the practical application of medical law. These examples are in no way to be regarded as all encompassing forms/precedents and are published for general information and are not intended as legal advice. As every situation depends on its own facts and circumstances, the purpose of the annexures is to provide practical guidance only. The examples of forms/precedents provided are therefore illustrative only. They lack specific content and substance and should under no circumstances be used as they stand. The authors and publishers therefore accept no responsibility for any consequences or damages of whatever nature flowing/arising from/brought about by the use of and/or reliance on the forms/precedents contained in the foregoing annexures by anyone."

[979] *Clarke v Hurst NO and others* 1992 4 SA 630 (D).

condition where the subject retains the capacity to maintain the vegetative part of neurological function but has no cognitive function. In such a state the body is functioning entirely in terms of its internal controls. It maintains digestive activity, the reflex activity of muscles and nerves for low level and primitive conditioned responses to stimuli, blood circulation, respiration and certain other biological functions but there is no behavioural evidence of either self awareness or awareness of the surroundings in a learned manner. … Steadman's Medical Dictionary defines "vegetative" as functioning involuntarily or unconsciously after the assumed manner of vegetable life.

It would seem to me that the term "persistent vegetative state" describes not a distinct condition but rather a range of chronically persistent neurological defects which are irreversible; with no cognitive or intellectual function and no self awareness or awareness of the surroundings and no purposive bodily movement."[980]

In the South African *Clarke v Hurst*[981] case the patient was in a "persistent vegetative state" and the court determined that life-prolonging treatment, specifically artificial feeding, could be withdrawn from the mentally incompetent patient.[982]

South Africa's former President Mandela's persistent vegetative state several months prior to his death, led to widespread media coverage.[983] The *Daily Maverick* reported that:

> "It is poignant that as Nelson Mandela lay in a "permanent vegetative state" towards the end of his life in June last year, doctors advised his family to turn off his life support machines. It was the ever-progressive and forward-thinking Mandela who had understood the urgency of end-of-life decisions and who in

[980] *Clarke v Hurst NO and others* 1992 4 SA 630 (D) 408-409.
[981] *Clarke v Hurst NO and others* 1992 4 SA 630 (D);
[982] See *Clarke v Hurst NO and others* 1992 4 SA 630 (D) case discussion in para 3.6.1. See discussion on the doctrine of double effect in para 5.10.4.
[983] Staff Reporters "Report: Nelson Mandela is in a 'vegetative state'" *Mail & Guardian* (4 July 2013) <https://mg.co.za/article/2013-07-04-report-nelson-mandela-is-in-a-vegetative-state> (accessed 16-09-2019).

1998 mandated the Law Commission, chaired then by the late Chief Justice, Ismail Mahomed, to compile the report and draft legislation on the issue."[984]

The *Mail & Guardian* reported that Mandela did not have a living will which might have prevented him from being put on life support in the first place.[985] Alternatively, Mandela could have provided instructions in his living will such as the placement of a limitation on a period to be kept in a persistent vegetative state, before ceasing life prolonging measures. Since Mandela gave no such instructions, Mandela's next of kin had to decide for themselves when life support measures could be stopped.[986]

In the English landmark *Bland*[987] decision, the National Health Service Trust sought a declaration that it could lawfully discontinue all life-sustaining treatment, including the withdrawal of ventilation, nutrition and hydration from a patient in a persistent vegetative state. The House of Lords found that continuing treatment was not in the patient's best interests and therefore the medical personnel could withdraw the treatment.

5.7 Dementia

According to Ash, dementia "is not a single disease, but rather a clinical state where a decline in cognitive function, such as loss of memory, judgement, language, complex motor skills and other intellectual functions, leads to a decline in independent daily function".[988]

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[984] Thamm M "The right to die: Archbishop Tutu provides guidance on the last medical, legal and ethical frontier" *Daily Maverick* (14 July 2014) <https://www.dailymaverick. co.za/article/2014-07-14-the-right-to-die-archbishop-tutu-provides-guidance-on-the-last-medical-legal-and-ethical-frontier/#.Wv2atEgo-Uk> (accessed 16-07-2019).

[985] Staff Reporters "Report: Nelson Mandela is in a 'vegetative state'" *Mail & Guardian* (4 July 2013) <https://mg.co.za/article/2013-07-04-report-nelson-mandela-is-in-a-vegetative-state> (accessed 16-09-2019).

[986] Staff Reporters "Report: Nelson Mandela is in a 'vegetative state'" *Mail & Guardian* (4 July 2013) <https://mg.co.za/article/2013-07-04-report-nelson-mandela-is-in-a-vegetative-state> (accessed 16-09-2019).

[987] See *Airedale National Health Service Trust v Bland* [1993] 1 All ER 821 case discussion in para 4.4.5.1.1.

[988] Ash EL "What is dementia?" in C Foster, J Herring & I Doron *The Law and Ethics of Dementia* (2014) 15.

The illness of dementia poses unique challenges when it comes to drafting and enforcing living wills and advance directives.[989] Not only does dementia pose challenges for advance directives and living wills, but Etheredge emphasises that "dementia represents one of the biggest challenges to the doctor-patient relationship".[990]

Due to medical advancements and improved health care, the population of the world is ageing. According to Doron the increase in the aging population leads to a wide spectrum of health-related consequences and dementia and Alzheimer's disease are the most common age-related conditions of our time.[991]

According to Dworkin:

> "In many respects, the demented person is in the same position as an unconscious, persistently vegetative patient. But there is an important difference. I can think about my best interests were I to become permanently vegetative with no concern about any conflict of interests: if I am convinced that it would spoil my life to be kept alive for years as a vegetable, I can act on that conviction with no prospect of conflict – by signing a living will directing that I be allowed to die. But I know that if I become demented, I will probably want to go on living, and that I may then still be capable of primitive experiential pleasures. Some dementia victims, it is true, lead frightful, painful lives, full of fear and paranoia. Some are brutally unpleasant and ungrateful to those who care for them. But even they appear to want to continue living. And how can I know that my life will be unpleasant?"[992]

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[989] See Burla C, Rego G & Nunes R "Alzheimer, dementia and the living will: a proposal" (2014) 17 *Medicine, Health Care and Philosophy* Springerlink 389–395.
[990] Etheredge H "Enhancing the doctor-patient relationship: living, dying and use of the living will" (2009) (MScMed (Bioethics & Health Law) Dissertation) 50.
[991] Doron I "The Demographics of Dementia" in C Foster, J Herring & I Doron *The Law and Ethics of Dementia* (2014) 15.
[992] Dworkin R "Life Past Reason" in *Life's Dominion* (1993) 230.

It is important to distinguish between the different stages (different degrees) of dementia and to discuss each stage in the living will document. The different stages vary so greatly that a drafter might want different approaches to his or her medical care depending on which stage he or she will be facing. The maker may want to address the different quality of life aspects which will be changing as the disease progresses. It is important to note that there is currently no cure for dementia and in the end people may totally lose the ability to make any decisions, whether trivial or important, for themselves.

Different documents have been developed to deal especially with the unique situation facing dementia patients.[993] These documents are generally subdivided into categories of mild, moderate and severe dementia to enable the patient to explain the different wishes when faced by each stage of the progression of the disease.

People may opt to sign living wills stipulating that should they become permanently or severely demented and thereafter develop a serious disease, they would not want to be given medical treatment except perhaps pain relief. In order to respect their autonomy, one would follow their wishes but what if the wishes are not in the best interests of the patient? As Dworkin phrases it, there may be a conflict between the patient's "precedent autonomy" and the patient's "contemporary experiential interests" if he or she is still enjoying life. However, there would not have been any conflict with his or her self-conceived critical interests and patient autonomy, if he or she was still competent to express his or her view. To address the conflict between the patient's best interests and autonomy, Dworkin suggests that the principle of paternalism should be ruled out and that the patient's critical interests as if the patient were still mentally competent, must be followed.[994]

[993] Gastner B "Advance Directive for Euthanasia" (2017) <https://dementia-directive.org/> (accessed 23-07-2019) below.
[994] Dworkin R "Life Past Reason" in *Life's Dominion* (1993) 231.

Dr Gastner, Professor of Medicine at the University of Washington School of Medicine, and his colleagues, aided by experts in neurology, geriatrics, and palliative care, have developed an advance directive for dementia patients. This directive has been published in the New York Times and elsewhere and is widely popular with 2000 downloads per month.[995] He also calls this directive an Alzheimer's-specific living will. The dementia directive is divided in terms of different stages of the illness. Stage 1 is for patients with mild dementia, Stage 2 for those suffering from moderate dementia and Stage 3 for patients with severe dementia. The maker is requested to tick the boxes that reflect his or her medical health care goals during the different stages of dementia. The advance directive provides the following:

"Health Directive for Dementia"

"Stage 1 -- Mild dementia

People may often lose ability to remember recent events in their lives.

Routine tasks become difficult (such as cooking.) Some tasks can become more dangerous (such as driving.)

If you were to be at this stage of dementia what level of medical care would you want for yourself?

Select one of the 4 main goals of care listed below to express your wishes. Choose the goal of care that describes what you would want at this stage.

If I had mild dementia then I would want the goal for my care to be:

□ To live for as long as I could. I would want full efforts to prolong my life, including efforts to restart my heart if it stops beating.

□ To receive treatments to prolong my life, but if my heart stops beating or I can't breathe on my own then do not shock my heart to restart it (DNR) and do not place me on a breathing machine. Instead, if either of these happens, allow me to die peacefully. Reason why: if I took such a sudden turn for the worse then my

[995] Gastner B "Advance Directive for Euthanasia" (2017) <https://dementia-directive.org/> (accessed 23-07-2019).

dementia would likely be worse if I survived, and this would not be an acceptable quality of life for me.

□ To only receive care in the place where I am living. I would not want to go to the hospital even if I were very ill, and I would not want to be resuscitated (DNR). If a treatment, such as antibiotics, might keep me alive longer and could be given in the place where I was living, then I would want such care. But if I continued to get worse, I would not want to go to an emergency room or a hospital. Instead, I would want to be allowed to die peacefully. Reason why: I would not want the possible risks and trauma which can come from being in the hospital.

□ To receive comfort-oriented care only, focused on relieving my suffering such as pain, anxiety, or breathlessness. I would not want any care that would keep me alive longer.

Stage 2 -- Moderate dementia

People lose the ability to have conversations, and communication becomes very limited.
People lose the ability to understand what is going on around them.
People require daily full-time assistance with dressing and sometimes toileting.
If you were at this stage of dementia what level of medical care would you want?

Select one of the 4 main goals of care listed below to express your wishes. Choose the goal of care that describes what you would want at this stage.

If I had moderate dementia then I would want the goal for my care to be:

□ To live for as long as I could. I would want full efforts to prolong my life, including efforts to restart my heart if it stops beating.

□ To receive treatments to prolong my life, but if my heart stops beating or I can't breathe on my own then do not shock my heart to restart it (DNR) and do not place me on a breathing machine. Instead, if either of these happens, allow me to die peacefully. Reason why: if I took such a sudden turn for the worse then my dementia would likely be worse if I survived, and this would not be an acceptable quality of life for me.

□ To only receive care in the place where I am living. I would not want to go to the hospital even if I were very ill, and I would not want to be resuscitated (DNR). If a treatment, such as antibiotics, might keep me alive longer and could be given in the place where I was living, then I would want such care. But if I continued to get worse, I would not want to go to an emergency room or a hospital. Instead, I would want to be allowed to die peacefully. Reason why: I would not want the possible risks and trauma which can come from being in the hospital.

□ To receive comfort-oriented care only, focused on relieving my suffering such as pain, anxiety, or breathlessness. I would not want any care that would keep me alive longer.

Stage 3 -- Severe dementia

People are no longer able to recognize loved ones and family members. People may be aware through the night, disruptive, and yelling.

Some may be calm or serene most or all of the time, but many become angry and agitated at times, and sometimes even violent toward people they love.

People need round-the-clock help with all daily activities, including bathing and assistance with all basic body functions.

If I had severe dementia then I would want the goal for my care to be:

□ To live for as long as I could. I would want full efforts to prolong my life, including efforts to restart my heart if it stops beating.

□ To receive treatments to prolong my life, but if my heart stops beating or I can't breathe on my own then do not shock my heart to restart it (DNR) and do not place me on a breathing machine. Instead, if either of these happens, allow me to die peacefully. Reason why: if I took such a sudden turn for the worse then my dementia would likely be worse if I survived, and this would not be an acceptable quality of life for me.

□ To only receive care in the place where I am living. I would not want to go to the hospital even if I were very ill, and I would not want to be resuscitated (DNR). If a

treatment, such as antibiotics, might keep me alive longer and could be given in the place where I was living, then I would want such care. But if I continued to get worse, I would not want to go to an emergency room or a hospital. Instead, I would want to be allowed to die peacefully. Reason why: I would not want the possible risks and trauma which can come from being in the hospital.

□ To receive comfort-oriented care only, focused on relieving my suffering such as pain, anxiety, or breathlessness. I would not want any care that would keep me alive longer.

Signature Date Print Name + Date of Birth"

5.8 Cessation of Artificial Feeding and Hydration

Gwyther states that it is because of the availability of advanced medical technology which might just prolong the dying process, that clinical decisions have to be made regarding withholding and withdrawing treatment.[996] In the *Clarke v Hurst*[997] and *Bland*[998] cases the cessation of treatment of patients in a persistent vegetative state were ordered. The treatments that were ceased included artificial feeding and hydration.

The Supreme Court of Appeal in the *Stransham-Ford*[999] decision said that a patient's right to refuse medical treatment also applies to artificial feeding. Therefore in instances where a person who can only be kept alive by artificial means, he or she may bring about their own death by refusing to accept nutrition and hydration. The Supreme Court confirmed that the right to refuse medical treatment is recognised in the rights to

[996] Gwyther L "Withholding and withdrawing treatment: Practical applications of ethical principles in end-of-life care" (2008) *SAJBL* 1 1 24.
[997] See *Clarke v Hurst NO and others* 1992 4 SA 630 (D) case discussion in para 3.6.1
[998] See *Airedale National Health Service Trust v Bland* [1993] 1 All ER 821 case discussion in para 4.4.5.1.1.
[999] *Minister of Justice and Correctional Services v Estate Late James Stransham-Ford* [2017] 1 All SA 354 (SCA) para 31.

dignity[1000] and bodily integrity[1001] as enshrined in the South African Constitution.[1002] The Appeal Court referred to the *Re Conroy*[1003] decision in which the court said that:

> "… declining life-sustaining medical treatment may not properly be viewed as an attempt to commit suicide. Refusing medical intervention merely allows the disease to take its natural course; if death were eventually to occur, it would be the result, primarily, of the underlying disease, and not the result of self-inflicted injury."

On the facts of the *Clarke* case, Dr Clarke had a living will and was a member of the erstwhile South African Voluntary Euthanasia Society (SAVES) at the time. However, the court did not directly refer to Dr Clarke's living will in coming to its finding that life-sustaining treatment can be withheld, and also did not venture an opinion on the legal recognition of his living will or living wills in general. Since this chapter includes aspects of drafting of living wills, the contents of Dr Clarke's living will should be noted. The living will was directed to his family, his physician and to any hospital and read as follows:

"A Living Will"
"If there is no reasonable expectation of my recovery from extreme physical or mental disability . . . I direct that I be allowed to die and not be kept alive by artificial means and heroic measures. I ask that medication be mercifully administered to me for terminal suffering even though this may shorten my remaining life. I hope that you who care for me will feel morally bound to act in accordance with this urgent request."

[1000] S 10 Constitution of the Republic of South Africa, 1996.
[1001] S 12(2)(b) Constitution of the Republic of South Africa, 1996.
[1002] See Chapter 2 on South African constitutional rights with reference to end-of-life decisions and living wills.
[1003] *Re Conroy* 486 A.2d 1209 (N.J.S.C. 1985) at 1224.

5.9 Pregnancy

The question of advance medical instructions and pregnancy came under scrutiny in the *Munoz*[1004] case. In the *Munoz* case a 33-year old paramedic (Munoz), who was 14 weeks pregnant at the time, was declared brain dead by physicians at John Peter Smith Hospital in Fort Worth, Texas, USA. Munoz was found unconscious and not breathing on the kitchen floor one night after she had risen to prepare a bottle for her young son. Munoz' husband, who is also a paramedic, suspected that she had a heart attack and initiated cardiopulmonary resuscitation, before she was rushed to the hospital. At the hospital the tests revealed that Munoz' brain had been without oxygen for one hour with fatal consequences. She was declared brain dead.

Her husband requested the hospital to remove her from the ventilator, but the hospital refused citing the Texas Health and Safety Code, which regulates the removal of life-sustaining treatment from a pregnant patient. The Texas Health and Safety Code however only refers to patients in a persistent vegetative state, and not to brain dead patients, therefore the hospital still refused. According to Nienaber there is a clinical and legal difference between brain death and PVS. Nienaber explains that:

> "PVS is a disorder of consciousness in which patients with severe brain damage are in a state of partial arousal rather than true awareness … In this state, patients show some measure of digestive ability and some reflex activity of muscles and nerves in response to stimuli, and in some cases are able to independently maintain respiration and circulation. Nevertheless, there is no real awareness of the person's surroundings or any other higher cognitive functions. After some time of being in a vegetative state, the patient is classified as being in a PVS."[1005]

[1004] *Munoz v John Peter Smith Hospital Cause* No 096270080-14. Tarrant County District Court 96th Judicial District Texas 24 January 2014 (unreported) <http://thaddeuspope.com/braindeath/pregnancy.html> (accessed 16-08-2019).

[1005] Nienaber A "Pregnant, dead, and on a ventilator: A few thoughts in response to Prof. McQuoid-Mason" (2014) *The South African Journal on Bioethics and Law* 7 2 47-50.

Munoz' husband applied to the court for an order that the hospital be compelled to remove his wife from the ventilator so that she could "die" and her body be released for burial. Munoz had indicated on a previous occasion to her husband and parents that she did not want to be kept alive by artificial means. Munoz' husband also wanted the Texas Health and Safety Code declared unconstitutional as he averred it had violated his deceased wife's right to make her own treatment decisions. He furthermore averred that the statute violated her right to equality as the statute differentiated between pregnant women and other non-pregnant or male patients.

In the United States of America a person is regarded as dead in accordance with the standards of accepted medical practice if there is an irreversible cessation of all brain function (brain death).[1006] The South African law also employs "brain death" as the standard for determining death.[1007] Two months after the application was brought, the court ruled that Munoz had already been dead in terms of the Texas Health and Safety Code and therefore the Code was not applicable to her. The court said it was thus not necessary to consider the constitutionality of the legislation.

Another aspect which is applicable to living wills and pregnancy is the termination of pregnancy. The Termination of Pregnancy Act[1008] promotes the reproductive rights of women in South Africa. The Act provides that each woman has the right to have an early, safe and legal termination of pregnancy. The Act contains different pregnancy timelines and procedures to be followed.

It is therefore necessary for females to consider their wishes regarding pregnancy and its termination in the form of a living will or advance directive should they no longer be mentally competent to express their wishes.

[1006] Uniform Determination of Death Act, Uniform Laws Annotated 589 (West 1993 and West Supp. 1997), 706 U.S.C. 1981.
[1007] See para 5.4.
[1008] Choice of Termination of Pregnancy Act, 92 of 1996.

5.10 Euthanasia and Assisted Suicide

5.10.1. Introduction and Definitions

Euthanasia and assisted suicide are currently legally criminalised in South Africa.[1009] There is a legal distinction between the terms active and passive euthanasia in South African law. Active euthanasia amounts to murder, while passive euthanasia may be legally allowed.

Active euthanasia occurs when a person intentionally and actively participates in causing the death of a terminally ill patient to end pain and suffering (for example by administering a fatal injection or dose of medicine).[1010] In South Africa this is currently unlawful and constitutes murder.[1011]

Passive euthanasia occurs when a person withdraws or withholds treatment from a terminally ill patient or a patient suffering from unbearable pain and the patient dies.[1012] The end result of the withdrawal or withholding of the treatment is that the patient dies. Nature is therefore left to take its course. The South African law currently provides that it is not unlawful to withdraw treatment and nourishment from patients in a permanent

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[1009] *Minister of Justice and Correctional Services v Estate Late James Stransham-Ford* [2017] 1 All SA 354 (SCA). Cf further discussions on the legalisation of assisted suicide and euthanasia in Dörfling DF *Genadedood in die Strafreg – 'n regsfilosofiese en regsvergelykende perspektief* LLM Verhandeling Randse Afrikaanse Universiteit (1991); Khumalo RG *Euthanasia and the withdrawal of medical treatment from mentally incompetent patients* LLM Dissertation University of Natal (1996); Berger M *A morally justified policy for assisted euthanasia* MPhil Dissertation University of Stellenbosch (2000); Grové LB *Framework for the implementation of euthanasia in South Africa* LLM Dissertation University of Pretoria (2007); Monnye SL *The reform of the law on euthanasia in South Africa: a burden or relief to doctors and their patients* LLM Dissertation University of the Witwatersrand (2001); Landman WA "A proposal for legalizing assisted suicide and euthanasia in South Africa" in Kopelman LM and De Ville KA (eds) *Physician-Assisted Suicide* (2001) Kluwer Academic Publishers 203-225; Egan A "Should the state support 'the right to die'?" (December 2008) 1 2 *SAJBL* 47-52; Landman WA "End-of-life decisions, ethics and the law: A case for statutory legal clarity and reform in South Africa: A Position Paper" 18 May 2012 (Ethics Institute of South Africa) 45-62; Welgemoed M *Euthanasia: a modern legal perspective* LLM Thesis Nelson Mandela Metropolitan University (2014).

[1010] *S v Hartmann* 1975 3 SA 532 (C).

[1011] *S v Hartmann ; S v De Bellocq* 1975 3 SA 538 (T); *S v Marengo* 1991 2 SACR 43 (W); *S v Smorenburg* 1992 2 SACR 389 (C).

[1012] *S v Hartmann* 1975 3 SA 532 (C).

vegetative state with no prospect of recovery.[1013] Thus it is lawful to terminate treatment in hopeless cases after all possible treatments or procedures (all non-invasive or invasive) have failed, so as to allow the patient to die naturally.[1014] The decision to withdraw or withhold treatment should be taken in conjunction with the relatives of the patient and if possible the patient.[1015] The same principles of withdrawing and withholding treatment should apply when turning off a pacemaker.[1016] In the *Bland*[1017] case the court said that to render useless treatment in hopeless cases, could indeed be regarded as unethical.

The South African Law Commission has produced a comprehensive working paper and a draft bill on the recognition of advanced directives and substituted judgments on behalf of terminally ill patients and those suffering from unbearable pain, as well as the legalisation of physician assisted suicide for such patients.[1018]

5.10.2 South African Law Commission: Draft Bill on End of Life Decisions

The South African Law Commission did not provide a specific proposal for active euthanasia, but merely set out different possible options.

Option 1: Confirmation of the current legal position: "No legislative enactment"

"The arguments in favour of legalising euthanasia are not sufficient reason to weaken society's prohibition of intentional killing since it is considered to be the cornerstone of the law and of all relationships. Whilst acknowledging that there may be individual cases in which euthanasia may be appropriate, these cannot establish the foundation of a

[1013] *Clarke v Hurst* 1992 4 SA 630 (D).
[1014] *Clarke v Hurst* 1992 4 SA 630 (D).
[1015] *Clarke v Hurst* 1992 4 SA 630 (D).
[1016] McQuoid-Mason D "Pacemakers and 'living wills': Does turning down a pacemaker to allow death with dignity constitute murder? (2005) *SACJ* 24-40.
[1017] Cf *Airedale NHS Trust v Bland* 1993 1 All ER 821 (HL).
[1018] SA Law Commission Report on *Euthanasia and the Artificial Preservation of Life* (1998).

general pro-euthanasia policy. It would furthermore be impossible to establish safeguards to prevent abuse."

Option 2: "Decision-making by a medical practitioner"

> "The practice of active euthanasia is regulated through legislation in terms of which a medical practitioner may give effect to the request of a terminally ill, but mentally competent patient to make an end to the patient's unbearable suffering by administering or providing a lethal agent to the patient. The medical practitioner has to adhere to strict safeguards in order to prevent abuse".

The Draft Bill elaborates on Option 2 and states that:

> "5(1) Should a medical practitioner be requested by patient to make an end to the patient's suffering, or to enable the patient to make an end to his or her suffering by way of administering or providing some or other legal agent, the medical practitioner shall give effect to the request if he or she is satisfied that:
>
> a) the patient is suffering from a terminal or intractable and unbearable illness;
> b) the patient is over the age of 18 years and mentally competent;
> c) the patient has been adequately informed in regard to the illness from which he or she is suffering, the prognosis of his or her condition and of any treatment or care that may be available;
> d) the request of the patient is based on a free and considered decision;
> e) the request has been repeated without self-contradiction by the patient on two separate occasions at least seven days apart, the last of which is no more [than] 72 hours before the medical practitioner gives effect to the request;
> f) the patient, a person acting on the patient's behalf in accordance with [subclause] (6), has signed a completed certificate of request asking the medical practitioner to assist the patient to end the patient's life;
> g) the medical practitioner has witnessed the patient's signature on the certificate of request or that of the person who signed on behalf of the patient;

h) an interpreter fluent in the language used by the patient is present in order to facilitate communication when decisions regarding the treatment of the patient are made where the medical practitioner as contemplated in this [clause] does not share or understand the first language of the patient;
i) ending the life of the patient or assisting the patient to end his or her life is the only way for the patient to be released from his or her suffering.

(2) No medical practitioner to whom the request to make an end to a patient's suffering is addressed as contemplated in [sub-clause] (1), shall give effect to such a request, even though he or she may be convinced of the facts as stated in that subsection, unless he or she has conferred with an independent medical practitioner who is knowledgeable with regard to the terminal illness from which the patient is suffering and who has personally checked the patient's medical history and examined the patient and who has confirmed the facts as contemplated in [sub-clause] (1)(a),(b) and (i).

(3) A medical practitioner who gives effect to a request as contemplated in [sub-clause] (1), shall record in writing his or her findings regarding the facts as contemplated in that [sub-clause] and the name and address of the medical practitioner with whom he or she has conferred as contemplated in [sub-clause] (2) and the last-mentioned medical practitioner shall record in writing his or her findings regarding the facts as contemplated in [sub-clause] (2).

(4) The termination of a patient's life on his or her request in order to release him or her from suffering may not be effected by any person other than the medical practitioner.

(5) A medical practitioner who gives effect to a patient's request to be released from suffering as contemplated in this section shall not thereby

suffer any civil, criminal or disciplinary liability with regard to such an act provided that all due procedural measures have been complied with.

(6) If a patient who has orally requested his or her medical practitioner to assist the patient to end the patient's life is physically unable to sign the certificate of request, any person who has attained the age of 18 years, other than the medical practitioner referred to in [sub-clause] (2) above may, at the patient's request and in the presence of the patient and both the medical practitioners, sign the certificate on behalf of the patient.

(7) (a) Notwithstanding anything in this Act, a patient may rescind a request for assistance under this Act at any time and in any manner without regard to his or her mental state.

(b) Where a patient rescinds a request, the patient's medical practitioner shall, as soon as practicable, destroy the certificate of request and note that fact on the patient's medical record.

(8) The following shall be documented and filed in and become part of the medical record of the patient who has been assisted under this [Draft Bill]:

(a) a note of the oral request of the patient for such assistance;

(b) the certificate of request;

(c) a record of the opinion of the patient's medical practitioner that the patient's decision to end his or her life was made freely, voluntarily and after due consideration;

(d) the report of the medical practitioner referred to in [sub-clause] (2) above;

(e) a note by the patient's medical practitioner indicating that all requirements under this [Draft Bill] have been met and indicating the steps taken to carry out the request, including a notation of the substance prescribed."

Option 3: Decision making by a panel or committee

The third option which the Draft Bill provides for the practice of active euthanasia is where a multi-disciplinary panel or committee is created to consider requests for euthanasia in accordance with the prescribed criteria.

The Draft Bill on End of Life Decisions describes this third option as follows:

"Option 3: Decision by panel or committee
Cessation of life

5(1) Euthanasia may be performed by a medical practitioner only, and then only where the request for the euthanasia of the patient has been approved by an ethics committee constituted for that purpose and consisting of five persons as follows:

a) two medical practitioners attending to the patient;
b) one lawyer;
c) one member sharing the home language of the patient;
d) one member from the multi-disciplinary team; and
e) one family member.

(2) In considering and in order to approve a request as contemplated in [sub-clause] (1) the Committee has to certify in writing that:

a) in its opinion the request for euthanasia by the patient is free, considered and sustained request;
b) the patient is suffering from terminal or intractable and unbearable illness;
c) euthanasia is the only way for the patient to be released from his or her suffering.

(3) A request for euthanasia must be heard within three weeks of it being received by the Committee.

(4) (a) The Committee which, under [subclause] (2), grants authority for euthanasia must, in the prescribed manner and within the prescribed period after euthanasia has been performed, report confidentially to the Director General of Health, by registered post, the granting of such authority and set forth –

(i) the personal particulars of the patient concerned;

(ii) the place and date where euthanasia was performed and the reasons therefore;

(iii) the names and qualifications of the members of the committee who issued the certificates in terms of the above sections; and

(iv) the name of the medical practitioner who performed euthanasia.

(b) The Director-General may call upon the members of the Committee required to make a report in terms of [subclause] (4) or a medical practitioner referred to in [subclause] (1) to furnish such additional information as he may require.

(5) The following shall be documented and filed and become part of the medical record of the patient who has been assisted under this [Draft Bill]:

(a) full particulars regarding the request made by the patient;

(b) a copy of the certificate issued in terms of [sub-clause] (2);

(c) a copy of the report made in terms of [sub-clause] (4).”

Allied Medical Professionals for Assisted Dying (AMPADSA) have elaborated on the safeguards contained in the Draft Bill on End of Life Decisions published to help protect vulnerable people requesting assisted dying.[1019] In terms of the Draft Bill a patient who

[1019] These safeguards are based on safeguards published by Death with Dignity, UK and legislation applicable to the American State Oregon <http://www.ampadsa.org/how/> (accessed 1-7-2019).

requests assistance in dying, will need to be assessed by two independent doctors and a psychiatrist.

The Draft Bill states that the two doctors will have to be satisfied that the patient has a terminal illness (with a prognosis of six months or less to live) or is indeed suffering intractably from an incurable, debilitating disease. AMPADSA suggests the two independent doctors must establish whether the request is well-informed, persistent & voluntary. The patient must have the mental capacity to make decisions.[1020] AMPADSA recommends a registered psychiatrist should evaluate the patient. The patient must be given full information available about end of life care options available (thus enabling the patient to give informed consent). AMPADSA suggests the patient must thus be informed about palliative and supportive care available. AMPADSA suggests that the patient's request must be witnessed independently.

The Draft Bill also states that a patient must have the ability to make a voluntary and informed decision free from outside pressure. There is further a 14-day mandatory period of reflection after the medical examinations and before the patient receives the medication. AMPADSA suggests that the 14-day period may be reduced to six days if the two doctors agree that the patient's death is expected to occur within one month. A request for an assisted death could be withdrawn or orally revoked at any time.

The Draft Bill thus excludes people who are not terminally ill or who are not suffering intractably from an incurable, debilitating disease. Patients who are not mentally competent, including those with dementia or Alzheimer's disease, even if they are terminally ill, are also excluded from the Draft Bill. Patients who are under the age of 18 are also excluded.

[1020] Cl 5(2)(a) Draft Bill on End of Life Decisions.

5.10.3 The South African Medical Association: Guidelines

The South African Medical Association has published the following guidelines for medical practitioners on the use of living wills, applicable to a request for euthanasia:

In these guidelines the SAMA defines “active euthanasia” as “the act of deliberately ending the life of a patient, even at the patient’s own request or at the request of close relatives”. “Assisted Suicide” on the other hand is defined as “the provision, but not the administration of a legal drug or weapon”.

The SAMA describes the doctor’s dilemma to treat a patient who may be suffering and terminally ill, as well as the dilemmas of patients who want the doctors to end their lives. The SAMA indicates that the doctors’ have to adhere to their oath to “preserve and protect life”, but “when people are suffering, empathy often becomes astoundingly overwhelming and trying to treat a person with dignity and allowing them to die with same intact, sometimes places [m]edical [p]ractitioners in a difficult position”.

In the euthanasia guidelines a “living will” is defined as follows:

> “A living will is drawn up when a patient is mentally competent. This document dictates his/her clear intentions, to the care givers and next of kin, as to what should or should not be done in the event of a permanent and incurable illness or condition. The terms may vary from active euthanasia to prescription of drugs the side effect of which may hasten death. The so-called living will is of course not a will in the true sense of the word. It is at best a declaration which a person in anticipation of certain future events, gives rise. We should also remind ourselves that every person has the right to refuse medical treatment of any sort, even if such refusal has the imminent death is expedited as a result thereof. We cannot deny that such a document is in essence, not legal at all. In the South African context and law, a person can’t give consent to be harmed/injured etc. Thus,

drafting a document in which you provide consent to be put to death, does not provide any legal argument which will stand in a [c]ourt".

The SAMA provides guidelines for what medical practitioners must do when confronted by a living will or request for active euthanasia or assisted suicide:

> "At the moment, when taking into account the current South African legislation, the only thing a medical practitioner can do is to refuse to act on the request for Active euthanasia/assisted suicide or for executing of a Living Will.[1021]
> In all instances, the action taken in bringing forth the result of death of a patient, will be deemed to be murder and will lead to a conviction for murder.
> Mitigating circumstances will be taken into account by the Court, but the validity of any argument which supports a medical practitioner in such an action, will be depleted by the fact that Section 9 of the Constitution provides every person in this country with the absolute right to Life.
> Should any practitioner be confronted with such a document or situation, the best thing to do is to report the request to the immediate Senior or Human Resources Manager and Superintendent of the Hospital.
> Further to the above, you can also contact SAMA for legal advice and confirmation of what has been set out in this document.
> It is of extreme importance that no action be taken in this regard, until the relevant management and superiors have been informed.
> Active Euthanasia, Assisted Suicide and Living Wills are illegal.
> Do not engage in providing assistance in any manner which could be seen as assistance to expedite, as this will result in a sure conviction for murder."[1022]

[1021] SAMA "Guidelines for Medical Practitioners on Living Wills prepared by the South African Medical Association (Policy since June 1994)" <https://www.samedical. org/images/attachments/guidelines-with-regard-to-living-wills-2012.pdf> (accessed 30-07-2019) 1.
[1022] SAMA "Guidelines for Medical Practitioners on Living Wills prepared by the South African Medical Association (Policy since June 1994)" <https://www.samedical. org/images/attachments/guidelines-with-regard-to-living-wills-2012.pdf> (accessed 30-07-2019) 1-2.

5.10.4 The Doctrine of Double Effect

According to Griffiths *et al:*

"The doctrine of double effect holds that behavior that has both a good and a bad effect can, despite the bad effect, be morally permissible provided

1. the behaviour itself is not intrinsically wrong (that is: considered separately from its consequences);
2. the actor intends only the good effect, not the bad one;
3. the bad effect is not a means used to bring about the good effect; and
4. the good effect outweighs the bad effect."[1023]

Griffiths *et al* explain that:

> "In order to ensure that the outcome of the doctrine of double effect corresponds with moral intuition, the term 'intention' in the second condition is interpreted in a special, narrow way. This can be understood as follows. Behavior can have three sorts of consequences: consequences desired for themselves; consequences desired as a means toward a result that is desired for itself; and consequences that are side-effects of the behavior. According to the narrow conception of the intentional, only the first two are to be considered 'intended', while side-effects are 'merely foreseen'. The doctrine of double effect rests, therefore, on the distinction between 'intention' and 'foresight of consequences'.[1024]

Griffiths et al further explain that:

> "Adherents to the doctrine of double effect conclude that shortening life as a result of alleviating pain is morally permissible because, although it can be foreseen, death in such a case is not desired either for itself or as a means of achieving the goal of alleviating suffering. What is desired is the alleviation of the patient's suffering. His death is not a means to achieve that goal, and

[1023] Griffiths J, Bood A & Weyers H *Euthanasia & Law in the Netherlands* (1998) 163.
[1024] Griffiths J, Bood A & Weyers H *Euthanasia & Law in the Netherlands* (1998) 163.

administering the same drug to cause the patient to die in order to put an end to his suffering would not be permissible."[1025]

"Ceasing treatment that is disproportionately burdensome, even if this will probably cause the patient to die is, according to adherents of the doctrine of double effect, also morally permissible. Shortening the patient's life is not considered a means of ending the burden to the patient but as a merely anticipated side-effect."[1026]

McQuoid-Mason describes the difficulty of the elements of intention, causation and unlawfulness, when a determination has to be made whether a doctor should be held liable for the crime of murder when a doctor withholds or withdraws treatment or prescribes palliative treatment that hastens the death of a patient.[1027] McQuoid-Mason states that in this scenario the doctor has the "eventual intention" to kill the patient even though he has a good motive. However there must also be factual and legal causation for a person to be held liable for murder. McQuoid-Mason explains that "doctors who hasten the death of a terminally ill or injured patient by withholding or withdrawing treatment of administering a potentially fatal dose of medicine will have legally [and factually] caused the death of the patient." It is however on the point of unlawfulness of the act or omission, that a doctor can be found not be liable for murder. McQuoid-Mason explains that:

"Whether or not a person's act or omission is unlawful will depend on the legal convictions of the community at the time. Although it is not possible for a person to consent to doctor-assisted suicide in the form of active euthanasia, it is trite that it is unlawful for a mentally competent patient to refuse medical treatment even if such refusal will result in their death.

[1025] Griffiths J, Bood A & Weyers H *Euthanasia & Law in the Netherlands* (1998) 163-164.
[1026] Griffiths J, Bood A & Weyers H *Euthanasia & Law in the Netherlands* (1998) fn23 164.
[1027] McQuoid-Mason DJ "Withholding and withdrawing treatment and palliative treatment hastening death: The real reason why doctors are not held legally liable for murder" (Feb 2014) 104 2 *SAMJ* 102-103.

The courts have also held that it is not unlawful to withdraw treatment from patients where the prognosis is hopeless and medical interventions would amount to a 'fruitless attempt to save the deceased's life'.[1028] … In cases where such treatment is withheld or withdrawn because: the patient has made an advance directive (e.g. a living will); the treatment would be futile; or the burdens and risks outweigh the benefits of such treatment (e.g the treatment may keep alive a severely brain-damaged patient), the courts and society do not regard the conduct as unlawful – despite the doctors knowing that their omissions or acts will result in the death of the patient. The courts have held that where the prognosis for a persistent vegetative patient is hopeless and their treatment 'did not serve the purpose of supporting human life as it is commonly known', the legal convictions of society would not regard the cessation of artificial feeding as unlawful."[1029]

5.10.5 Case Law

When assisted dying or mercy killing is performed, the courts usually convict the accused person on the charge of murder. Mercy killing or assisted suicide on request of the deceased (consent to murder), is not a valid defence for murder, but could affect the sentence imposed. Even if the perpetrator had noble intentions to help the deceased in terms of pain relief and suffering, these noble intentions might have an effect on the sentence imposed, but not the finding of guilt. The accused will still be convicted of murder, notwithstanding his or her good intentions.

[1028] *S v Williams* 1986 (4) SA 1188 (A).
[1029] *Clarke v Hurst NO and others* 1992 4 SA 630 (D); McQuoid-Mason DJ "Withholding and withdrawing treatment and palliative treatment hastening death: The real reason why doctors are not held legally liable for murder" (Feb 2014) 104 2 *SAMJ* 103.

5.10.5.1 *Clarke v Hurst*

In the South African *Clarke v Hurst*[1030] the issue of withdrawing life-prolonging treatment from a patient in a "persistent vegetative state" was queried. In this case the court determined that life-prolonging treatment, specifically artificial feeding, could be withdrawn from the mentally incompetent patient.[1031]

5.10.5.2 *S v Hartmann*

In the *S v Hartmann*[1032] case a medical practitioner was convicted of the murder of his father. Dr Hartmann's father was close to death and in severe pain as a result of widespread cancer. There was no option of a cure. Dr Hartmann's father did not have a living will, but had told the son about his end-of-life wishes. The father died as a result of Dr Hartmann administering a lethal dose of pentothal. The court held that the accused clearly possessed the requisite intention which was an essential element of murder. Even if it could be found that the deceased had consented to the administration of the drugs, it would not constitute a defence to the charge of murder. Although this mercy killing amounted to murder, leniency was expressed in the sentence imposed. The sentence of one year's imprisonment was wholly suspended on certain conditions. The accused had to remain in custody until the rising of court. The court said that if what the accused had done was merely to wilfully hasten the death of the deceased who would have died in any event, it still amounted to murder. What the prosecution had to prove was "but for" the actions of the accused, the deceased would not have died when he or she in fact did.

[1030] *Clarke v Hurst NO and others* 1992 4 SA 630 (D).
[1031] See *Clarke v Hurst NO and others* 1992 4 SA 630 (D) case discussion in Chapter 3 para 3.6.1.
[1032] *S v Hartmann* 1975(3) SA 532 (C).

5.10.5.3 *Stransham-Ford v Minister of Justice and Correctional Services*[1033]

The latest South African decision regarding end-of-life decisions is the *Stransham-Ford* Appeal case.[1034] In this case the applicant (Mr Stransham-Ford), suffering from terminal prostate cancer and close to death, brought an urgent application in the North Gauteng High Court for a declaratory order to the effect that he be allowed to request that a medical practitioner assist in ending his life either by authorising a doctor to administer a lethal dose of medication to him, or to provide him with a lethal dose that he could administer himself; that the medical practitioner will not be held accountable, be free of any civil, criminal or disciplinary liability; and that the common law be developed in line with the Constitution to give effect to the applicant's wishes. The applicant however passed away two hours before the court granted the declaratory order. This was a crucial point in the Supreme Court of Appeal case.

In its judgment, the court *a quo*, the North Gauteng High Court found that in the specific circumstances of the case, the applicant was indeed entitled to be assisted by a willing and qualified medical practitioner in ending his life.[1035] The court found that in the context of assisted suicide by medical practitioners, the common law crimes of murder or culpable homicide provide for an absolute prohibition of assisted suicide, which unjustifiably limits the applicant's constitutional rights to human dignity[1036] and freedom to bodily and psychological integrity[1037] and to that extent these crimes are declared to be overbroad and in conflict with the said provisions of the Bill of Rights. Furthermore the court found that the medical practitioner would not be considered to be acting unlawfully and thus not be subject to prosecution by the Director of Public Prosecutions (the third respondent) or disciplinary proceedings by the Health Professionals Council of South Africa (HPCSA) (the fourth respondent).

[1033] *Stransham-Ford v Minister of Justice and Correctional Services* [2015] 3 All SA 109 (GP).
[1034] *Minister of Justice and Correctional Services v Estate Late James Stransham-Ford* [2017] 1 All SA 354 (SCA). This thesis covers the legal position until 11 September 2019.
[1035] *Stransham-Ford v Minister of Justice and Correctional Services* [2015] 3 All SA 109 (GP).
[1036] S10 Constitution of the Republic of South Africa, 1996.
[1037] S12(2)(b) read with S1 and S7 Constitution of the Republic of South Africa, 1996.

The Minister of Justice and Correctional Services, the Minister of Health, the National Director of Public Prosecutions and the HPCSA took the case on appeal to the Supreme Court of Appeal.

5.10.5.4 *Minister of Justice and Correctional Services v Estate Late Robert James Stransham-Ford*

The Supreme Court of Appeal (the SCA) set aside the order of the Gauteng High Court on three inter-related grounds. The first ground for setting aside the order was based on the nature of Mr Stransham-Ford's claim. The SCA found that Mr Stransham-Ford's claim was entirely personal to him and when he died, his claim ceased to exist, therefore the High Court no longer had any authority to make an order on his application, as had been done. The SCA added that when Judge Fabricius' attention was later drawn to the fact that Mr Stransham-Ford had died before the order was given, the Judge should have rescinded the order made in error. The SCA said that the order gave Mr Stransham-Ford and any doctor who had assisted him, an exemption from the ordinary operation of criminal law, which is impermissible.

The SCA found that the second ground for setting aside the order was based on an error in law. The SCA said that the High Court had proceeded from an incorrect view of the current state of the law and had failed to distinguish between the legal implications of an order authorising a medical practitioner to administer a lethal substance to a patient with the latter's consent and the situation where a medical practitioner prescribes drugs that a patient could take if he or she wished to do so in an act of suicide. The SCA said that the action of a medical practitioner who administers a lethal substance to a patient, even with a patient's consent, amounts to murder. The fact that consent is given, is irrelevant, because consent to being killed does not affect the unlawfulness of the act causing the person's death.

The SCA found that there is no case law dealing with the situation in which a medical practitioner had prescribed drugs to a patient to be taken by the patient as an act of suicide if he or she so wished. The SCA said that if such a case were to arise, it would have to be judged according to the general principles of criminal law. The SCA found that the High Court had been wrong to find that prescribing the drugs would not necessarily constitute the crime of murder or any crime at all, but added that this would be a factual enquiry and could only be determined in the light of the circumstances of a particular case.

The SCA also remarked that the High Court failed to consider the broader implications of its decision on the South African criminal law system by making the order specific to Mr Stransham-Ford alone. The SCA found that since Mr Stransham- Ford had died, there was no need for the High Court to develop the common law in relation to murder and culpable homicide. The SCA noted that any such development would have required a more detailed consideration of the legal position and of international jurisprudence, in the light of South Africa's very different society from those in countries where some forms of physician assisted dying are permitted.

The SCA found that the third ground for setting aside the order of the High Court was the urgency of the application and inadequate factual records. The SCA said that because the case had been conducted on an urgent basis, it resulted in an inadequate record as far as the facts were concerned. It was not disclosed to the High Court that Mr Stransham-Ford had expressed reservations to his doctor about committing suicide, nor was the court informed that he had lapsed into a coma before the case was heard. The case was heard as a matter of urgency in an endeavour to dispose of it before Mr Stransham-Ford's imminent death. The SCA found that the fact that there were inadequate factual records prevented the court from having evidence before it that would have enabled it to deal with all the complex issues surrounding the development of the common law in this area. The SCA referred to the fact that in constitutional cases involving an alleged breach of a person's rights under the Bill of Rights, the

Constitutional Court had stressed the need for the case to be advanced on a proper factual basis and with a full consideration of the relevant law, both local and international, and pointed out that this case did not have the required factual basis.

The SCA noted that the applications by several parties to the appeal to place further evidence before court, indicated the inadequacy of the factual record. The SCA held that it was unsatisfactory for any court to determine issues of such importance without the evidence to demonstrate the impact of its decision in the context of South African society, which was differently constituted and faced different challenges compared to other jurisdictions.

As a result the SCA upheld the appeal and set aside the order of the High Court.

In this case the positions of advance directives or living wills were not discussed as the Applicant was still competent to convey his own health care instructions.[1038]

In the *Stransham-Ford* Appeal case the Court of Appeal said that it had to discuss the law with reference to assisted suicide, as the High Court case set a wrong precedent. In the New Zealand *Seales*[1039] case, the High Court's decision was referred to as the legal position in South Africa, therefore the Supreme Court of Appeal felt compelled to deal with the merits of the High Court's decision to curb the precedential effect of the High Court's decision.

The court summarised the legal position as follows: The acts of suicide and attempted suicide are not crimes in South Africa. The definition the court used confirmed that the act of suicide is "commonly understood as being the act of a person in intentionally bringing about their own death".[1040] The court referred to the *R v Peverett* [1041] case as

[1038] See full discussion on the legal position of assisted dying in South Africa in Chapter 6.
[1039] *Seales v Attorney-General* [2015] NZHC 1239 para 66.
[1040] *R v Peverett* 1940 AD 213 para 30.
[1041] *R v Peverett* 1940 AD 213.

its authority. In the *R v Peverett* case the accused and his girlfriend, Mrs Saunders, concluded a suicide pact. Peverett attempted to use carbon monoxide poisoning to kill them. He connected the exhaust pipe of the car to the interior and they sat in the car with windows closed and the engine running. Peverett's action did not have the intended result, as they both survived the suicide attempt. The court found that the accused clearly had the desire for them both to die, and had the required intention to cause Mrs Saunders' death but since she survived he could only be held liable for attempted murder and not murder. The court also confirmed that neither suicide, nor attempted suicide is criminalised in South Africa. However the court said that consent is not a valid defence on a charge of murder. The fact that the victim was free to prevent her own death, also did not free the accused from criminal liability.

The court said that a person may refuse treatment that would otherwise prolong life. "This is an aspect of personal autonomy that is constitutionally protected and would not ordinarily be regarded as suicide. Medical treatment without the patient's consent is regarded as an assault so that the patient is always entitled to refuse medical treatment. In refusing treatment the patient is allowing the natural processes of their disease to take their course".[1042]

The court then referred to cases of "mercy killings" in South Africa, which the High Court tried to use as precedents to develop the common law. These were *S v Hartmann*, *S v De Bellocq* and *S v Marengo*.

See the discussion of *S v Hartmann* in 5.10.5.2. In the *S v De Bellocq*[1043] case the accused, a medical student, gave birth to a premature infant who was shortly after birth diagnosed with toxoplasmosis. He was severely disabled, had to receive nourishment through a nasal-gastric tube and was grievously mentally handicapped. Due to De Bellocq's medical training she was fully aware that the child would have a very

[1042] *Minister of Justice and Correctional Services v Estate Late James Stransham-Ford* [2017] 1 All SA 354 (SCA) para 31.
[1043] *S v De Bellocq* [1975] 1 All SA 6 (T).

challenging life and impulsively drowned the baby in the bathwater. The court found her guilty of murder, but due to the unique circumstances of the case the court used its discretion and gave the accused a very light sentence.[1044] The accused was released on her own recognisance on condition to return to court for sentencing if, and when, called upon to do so, but she never was. In *S v Marengo*[1045] the accused shot her father, a cancer patient who was in mental decline. The accused was convicted of murder, but she did not receive a custodial sentence.

A further case that the High Court relied on to develop the common law was *Re Grotjohn*. In the *Grotjohn* case Mr Grotjohn was accused of murdering his wife. Mr Grotjohn handed a loaded firearm to his wife and stated the words: "Skiet jouself dan as jy wil, want jy is 'n las." The deceased aimed the firearm at her face and used her toes to pull the trigger. The court had to interpret the causal connection between the accused's action of handing the firearm to his wife and his wife pulling the trigger, killing herself. The court found that the end result was not removed far enough to be considered an independent or unexpected act and found that the causal chain of events between the accused's actions and the death of his wife, was not broken. In terms of the principle of fault, the court said that the accused could reasonably have foreseen that the deceased would have followed through with her promise to commit suicide and decided to reconcile himself with the result of his actions, instead of taking action to avert her death. The deceased thus had the necessary fault in terms of the principle of *dolus eventualis.*

The Supreme Court of Appeal in *Stransham-Ford* reiterated that consent is not a defence available to a person who brings about the death of another and is charged with murder. The court said that the fact that consent was provided does not justify a conviction on a lesser charge of culpable homicide.[1046] The Supreme Court held that

[1044] The court exercised its discretion in terms of s439 of the Criminal Procedure Act.
[1045] *S v Marengo* 1991 (2) SACR 43 (W).
[1046] Professor Sean Davison was charged on three counts of murder for assisting 3 persons to die. The three persons did provide consent, but the charge remained murder. See Chapter 5 para 5.10.6.1.

physician assisted suicide also constitutes murder under South African law and that it was wrong of the High Court to attempt to develop the common law on the facts of the urgent application before it and the insufficient record of evidence that it had before it.

5.10.6 Media Reports on Cases

5.10.6.1 Sean Davison: Plea and Sentencing Agreement

Professor Sean Davison, the current Chairperson of the International Federation of Right to Die Societies and co-founder of DignitySA, an organisation that fights for law change in South Africa with reference to assisted dying and euthanasia matters, was arrested for the premeditated murders of three persons whom he aided with assisted suicide between 2013 and 2015.[1047]

"DignitySA's vision is a "world where every individual is afforded the basic human right to self-autonomy in end-of-life decisions". Their mission is described as "to advocate for a change in South African laws that would enable mentally competent adults the option of a dignified death, should they so choose". They state that they "aim to do so by fighting unjust laws, addressing the Constitutional Courts and educating South Africans on their current and potential rights and options".[1048] According to Landman Dignity SA "is 'n burgerlike organisasie met die doel om wetgewing te help ontwikkel wat dit moontlik sal maak vir "kompetente persone om uit eie keuse menswaardig te sterf. Wanneer pasiente teen hul wil, onnodig en sinloos ly as gevolg van fisieke of geestelike pyn wat ontoereikend hanteer word, of wanneer 'n lewe sinloos verleng word, lei dit tot sterwe ontdaan van menswaardigheid".[1049] Since assisted suicide is currently still criminalised under the South Africa law, Davison was charged with three counts of

[1047] Sean Davison was appointed as the Chairperson of the World Federation Right to Die Societies in 2016. Willem Landman is the other co-founder of DignitySA. See DignitySA's website "Executive Committee" <https://dignitysouthafrica.org/executive-committee> (accessed 15-08-2019).
[1048] Dignity SA "Our vision" <https://dignitysouthafrica.org/our-vision> (accessed 15-08-2019).
[1049] Landman W "'n Stryd om lyers se waardigheid" in *Wreed én mooi is die dood: Verhale van verlies, hunkering en heling* (2019) 91.

premediated murder. Before the pre-trial hearing took place, Davison entered into a plea agreement with the state prosecutor in terms of which he admitted guilt to the three charges and agreed to serve three years' house arrest and eight years of imprisonment. However, the eight years' imprisonment sentence was fully suspended for five years on certain conditions including that he not be found guilty of murder, attempted murder or another serious crime within the next five years. The plea agreement was made an order of court on 19 June 2019. The three charges of premeditated murder related to Davison assisting the following three individuals in ending their lives: Anrich Burger, Justin Varian and Mike Holland. In all three cases the individuals requested Davison's help in ending their lives.

In terms of the plea agreement Davison will now serve three years under house arrest, during which time he cannot leave his house except for work, to visit a doctor or to carry out religious worship. He is also required to undertake 16 hours of community service each month.

This matter has generated a lot of public interest and public opinion as can be seen by all the media reports and opinion pieces.[1050]

The Plea and Sentence Agreement[1051] states that Davision was charged with the following three counts of murder.[1052]

"COUNT ONE

[1050] See Landman W "Opinion: A victim of law the injustice of Davison murder charges" (24 May 2019) *Times Live* <https://www.timeslive.co.za/ideas/2019-05-24-opinion-a-victim-of-law-the-injustice-of-davison-murder-charges/> (accessed 22-06-2019); de Vos P "The case of Professor Sean Davison and the right to die with dignity" *Constitutionally Speaking* blog <https://constitutionallyspeaking.co.za/the-case-of-professor-sean-davison-and-the-right-to-die-with-dignity/> (accessed 22-06-2019).
[1051] In terms of section 105A of the Criminal Procedure Act, 51 of 1977.
[1052] Charged with murder as described in section 51(1) and Part I of Schedule 2 of the Criminal Law Amendment Act, 105 of 1997.

IN THAT upon or about 2 November 2013 and at or near the Radisson Hotel, Beach Road, Granger Bay, in the district of Cape Town, the accused unlawfully and intentionally killed ANRICH BURGER, an adult male person, by administering a lethal amount of drugs to the quadriplegic deceased.

The deceased, Anrich Burger, was a medical doctor who was rendered a quadriplegic after a motor vehicle accident in 2005.

Subsequent to the motor vehicle accident and being left a quadriplegic, the deceased on more than one occasion expressed a desire to end his life. He suffered severe neuropathic pain in his legs and was totally dependent on others.

The accused is a founder member of Dignity SA, an organisation that advocates the right to assisted dying

Prior to the death of the deceased, the accused and the deceased met. Thereafter they had numerous meetings to discuss the deceased ending his life.

It was during these meetings that the accused agreed to assist the deceased in ending his life.

In execution of the plan to end his life, the deceased met the accused on 2 November 2013 in close proximity to the Radisson Hotel in Granger Bay.

The deceased, with the help of his assistant, booked himself into the Radisson Hotel. The accused remained outside.

The assistant left the hotel and the deceased remained behind in his hotel room.

The accused entered the hotel. The accused and deceased were alone in the deceased hotel room prior to his death.

The deceased, being a quadriplegic, was unable to consume medication on his own.

The accused caused the deceased's death by administering a lethal concoction of drugs to the deceased.

The accused left the hotel room and thereafter made contact with the deceased's assistant, fiancée and mother.

The cause of death was consistent with a multiple drug overdose.

COUNT TWO

THAT upon or about 25 July 2015 and at or near Bordeaux Court, Fresnaye, in the district of Cape Town, the accused unlawfully and intentionally killed JUSTIN VARIAN, an adult male person, by placing a bag over the deceased head and administering helium with the intent of helium deoxygenation and/or asphyxiation.

During 2010 the deceased, Justin Varian, suffered a stroke. In 2011 he was diagnosed with Motor Neuron Disease.

From 2012 until his death, the deceased was bedridden and suffered tremendously. The deceased had great difficulty eating, swallowing and sleeping. He was unable to move without assistance. The deceased often expressed his wish to die and asked family members and friends to respect his wishes.

The deceased approached the accused to assist him to end his life.

Prior to the death of the deceased, the accused and the deceased met, and the accused agreed to assist the deceased in ending his life.

On 25 July 2015 the accused arrived at the deceased's flat in Fresnaye and confirmed with the deceased that he no longer wished to live.

Due the deceased's immobility and the fact that he had difficulty swallowing, the accused placed a bag over the deceased's head and attempted to make use of helium deoxygenation as a method to end the deceased's life.

The equipment that was used was not fit for purpose and the initial technique used was inadequate.

The accused then ended the deceased's life by asphyxiation and or helium deoxygenation.

On the same day it was certified that the deceased had died from natural causes. The deceased was subsequently cremated and the true cause of death could not be anatomically determined.

COUNT THREE

IN THAT upon or about 8 November 2015 and at or near Fern Close, Constantia, in the district of Wynberg, the accused unlawfully and intentionally killed RICHARD HOLLAND, an adult male person, by administering a lethal amount of drugs to the deceased.

The deceased, Richard Holland, was a keen sportsman who was extremely fit and active.

On 11 October 2012 he was knocked off his bicycle whilst on a training ride in Dubai.

As a result of the accident, the deceased suffered brain injuries and had no motor function. He was unable to speak and had no audible voice. All communication was done through eye movements or agreement to a verbal alphabet in order for the deceased to spell the word that he wished to communicate. He could not feed himself and was fed through a tube in his stomach. Towards the end of his life, he was able to swallow soft food. He experienced extreme pain which included severe migraines and body pain from severe spasticity of his muscles.

On numerous occasions, the deceased expressed the desire to end his life. He requested the accused to be approached to assist him to end his life.

The accused visited the deceased and after a long consultation, the accused agreed to assist the deceased to commit suicide.

On 8 November 2015 the accused attended the deceased's home in Fern Close, Constantia. The accused enquired from the deceased, in the presence of his family, whether he still wished to commit suicide. The deceased confirmed that he did. On the same day, the accused administered to the deceased a lethal dose of fluid, containing pentobarbital, which subsequently caused the death of the deceased.

The deceased's cause of death was due to pentobarbital toxicity.

The accused admits, in respect of each of the counts, that he intended to cause the death of each of the deceased, that his actions did in fact cause the death of each of the deceased and that such conduct was unlawful and punishable by law."[1053]

Davison (the accused) agreed to the following sentence:

[1053] Original paragraph numbering omitted.

“The accused is sentenced to three years correctional supervision in terms of section 276(1)(h) of the Criminal Procedure Act, No. 51 of 1977. The correctional supervision will consist of the following measures:

i) That the accused is placed under house arrest for the full duration of the three years of correctional supervision except for the purposes of work, religious activity and attending a bona fide medical practitioner.

ii) The accused may not leave the magisterial district of his residence or place of work without the permission of his Correctional Supervision Officer.

iii) The accused [shall] perform voluntary community service as determined by the Correctional Supervision Officer. The community service shall not be less than sixteen hours per month. The Commissioner may suspend the number of hours partly or readjust them depending on the accused[‘s] cooperation with conditions in general.

iv) The accused is obliged to attend programmes as identified by Correctional Services as well as any other programmes, which may become necessary. Programmes will be under the supervision and determined by the Correctional Supervision Officer.

v) For the full duration of this sentence [the accused shall] refrain from using any alcohol or drugs other than those prescribed by a medical practitioner.

vi) The accused submits to being monitored by the Commissioner in order to achieve the objectives of the sentence; and

vii) The accused shall:

a. Before 20 June 2019 at 13h00 report to the Cape Town Community Corrections Office;

b. Obtain the written permission of the Commissioner before he changes his residential address; and
c. Comply with any reasonable instruction concerning the compliance with the administration of the sentence or any other condition issued by the Commissioner of Correctional Services or its representatives.
Further, the accused is sentenced to eight years direct imprisonment which is wholly suspended for a period of five years on condition that the accused is not convicted of murder, conspiracy to commit murder, attempted murder or a crime involving violence in which a sentence of direct imprisonment is imposed without the option of a fine, committed during the period of suspension.
The parties agree and submit that the proposed sentence is fair and reasonable and that the accused ought to be sentenced accordingly.
The Honourable Court declare the accused unfit to possess a firearm in terms of section 103 of the Firearms Control Act, No. 60 of 2000."

The factors that were taken into account for the sentencing were the following:

"The gravity of the offence, the interests of the community and the personal circumstances of the accused have duly been considered and taken into account by both parties.

The aggravating factors are as follows:

a. The offences are very serious.

b. Although the accused has no previous convictions in South Africa, he was convicted and sentenced in New Zealand for a similar offence. In 2011, he was convicted of counselling and procuring his mother to commit suicide. The accused was sentenced to home detention for a period of five months.

c. The accused knew his actions were unlawful, he nevertheless took the law into his own hands.
d. The accused is not a medical doctor and he was not qualified to perform medical procedures.
e. In performing procedures that he was unqualified to do, he ran the risk of causing pain, suffering and distress to those that were already suffering, as was the case of the deceased in count two, Justin Varian."

The following mitigating factors were taken into account:

"a. […] correctional supervision report drafted in respect of the accused by the Correctional Officer, Ms M Y Kwakwa.
b. The accused is fifty eight years old.
c. The accused is married and has three minor children, a ten year old son, an eight year old son, and a five year old daughter.
d. The accused is employed as a Professor of Bio – Technology at the University of the Western Cape.
e. His plea of guilty brought closure to the family of the deceased. It has spared the Court and the State the expenses of a protracted trial and the witnesses the ordeal of testifying and being cross-examined.
f. By pleading guilty the accused is minimising the potential trauma which the trial might have on the family of the deceased and some of the witnesses.
g. The accused is remorseful for his actions."

The parties are in agreement that there are substantial and compelling factors in terms of Section 51(3)(a) of Act 105 of 1997 which warrants a departure from the applicable minimum sentence of life imprisonment.[1054]

[1054] See Evans J "Why right-to-die activist Sean Davison is going home and not to jail for murder" (19 June 2019) *News24* <https://m.news24.com/SouthAfrica/News/why-right-to-die-activist-sean-davison-is-going-home-and-not-to-jail-for-murder-20190619> (date accessed 3-07-2019).

DignitySA published the following statement:

> **"**DignitySA is greatly relieved that our colleague, Professor Sean Davison, will not serve any prison sentence for having compassionately assisted three individuals to end their lives at their request. Those individuals' suffering could not have been ended in any other dignified way than with the selfless intervention of a good Samaritan.
>
> We thank the prosecuting authority, advocates and judges who recognised implicitly that there is something seriously amiss in our constitutional and legal system if assisted dying is equated with murder committed by a criminal with evil intent.
>
> Of course, the outcome of the plea bargain means that the principled and constitutional arguments for assisted dying were not deliberated by the court.
>
> However, it would have been a gross injustice if Prof Davison were to have been deprived of his liberty and family life, for what could have been many years, for a constitutional issue that the South African parliament has egregiously failed to address for more than 20 years.
>
> This failure has been the case despite the publication of a report by the South African Law (Reform) Commission on end-of-life decisions researched and written at the request of President Nelson Mandela.
>
> In addition, a full bench of the Supreme Court of Appeal (SCA) is on record that there is a deficiency in our law in so far as our common law and Constitution are not on the same page in respect of assisted dying.
>
> In future, when a court addresses this tension, a desirable outcome would be that the court follows the Canadian precedent and brings this to the attention of parliament in order for it to pass legislation consistent with our constitutional rights.
>
> Parliament has a duty to address and recognise the constitutional rights of people who suffer and die in intractable and unbearable circumstances. Unlike several other groups in our society, they have not had their constitutional rights

recognised. Moreover, they are extremely vulnerable because they lack the requisite political power to claim their constitutional rights.

DignitySA trusts that the application in the North Gauteng High Court, by Mr Dieter Harck, who is suffering from motor-neurone disease, will rectify what the SCA has identified as a "deficiency" in our law.

Indications are that there is significant and ever increasing public support for decriminalising assisted dying in South Africa.

DignitySA wishes to thank the media for keeping the debate about assisted dying alive and informing the public about the issues at stake".[1055]

Davison published the following statement via DignitySA:

"In a plea bargain agreement with the South African court I pleaded guilty to the charges I faced and received a three year house arrest sentence at my home in Cape Town.
I know there will be many people disappointed that I accepted a plea bargain, and did not go to trial. If I had done this I may have been found not guilty, and thereby lead to a law change. However, I was facing three life sentences in prison and the stakes were too high. I have three young children and my children want a father not a martyr.
I want to thank the thousands of people in South Africa and around the world who have sent messages of support and encouragement. The nine months since my arrest has been a harrowing journey, and this kind support has made it bearable."

5.10.6.2 Karel Schoeman

The writer Karel Schoeman's death in 2017 led to considerable media coverage. Schoeman was not terminally ill or in great pain, he simply wanted to die. Karel Schoeman contacted Professor Willem Landman the co-founder of DignitySA to request information on the various options of committing suicide and the legal implications thereof, if someone were to assist him. Professor Landman was very open about the

[1055] DignitySA "Statement by DignitySA" (20 June 2019) <https://dignitysouthafrica.org/> (accessed 23-06-2019)

fact that Karel Schoeman requested information from him. In the book "*Wreed en mooi is die dood: verhale oor verlies, hunkering en heling*"[1056] Landman writes about his communications with Karel Schoeman. Landman gave Schoeman information on methods of self-deliverance including fasting, taking prescribed medication, drinking agricultural poisons, drowning etc. Landman also advised Schoeman to sign a living will. In the end Landman put Schoeman in contact with a professional person (known as person "X") with scientific knowledge of substances to take for self-deliverance and who would be able to obtain the substance and act in his private capacity to assist Schoeman. Person X sent the necessary substance via a courier company to Schoeman and Schoeman self-administered the substance and passed away.[1057] Schoeman's death certificate states that he died of natural causes.[1058] Schoeman left a suicide note which he titled "Verklaring" (Statement). In this *Verklaring* he stated that if he managed to succeed with his current suicide attempt, he would hope that all those people who were involved will talk freely to the outside world about it. He said that he hoped that his death would contribute to a wide discussion of old age and self-determination which might bring about amendments to the current South African law regarding self-determination.

5.10.6.3 South Gauteng High Court Application: Dieter Harck

According to media reports Dr Sue Walters (terminal cancer patient) and Dieter Harck (motor neuron disease patient) approached the South Gauteng High Court for a declaratory order to allow assisted dying[1059] This case was not brought on an urgent

[1056] Landman W "Karel Schoeman: Sy laaste dae en wense" in Wiese T (comp) *Wreed én mooi is die dood: Verhale van verlies, hunkering en heling* (2019) 95-108.
[1057] Wiese T *Wreed én mooi is die dood: Verhale van verlies, hunkering en heling* (2019) 95.
[1058] La Vita M "Eksklusief: Só her Karel Schoeman gesterf" *Netwerk 24* (23 Feb 2018) <https://www.netwerk24.com/Stemme/Profiele/eksklusief-so-het-karel-schoeman-gesterf-20180222> (accessed 13-09-2019).
[1059] Marx J & Theron N "Terminally ill doctor and patient call for the right to euthanasia" *News24* (20 September 2017) <https://www.news24.com/SouthAfrica/News/terminally-ill-doctor-and-patient-call-for-the-right-to-euthanasia-20170920> (accessed 22-06-2019).

application basis, so that the full record and all evidence could be considered[1060]. The Supreme Court of Appeal ("SCA") remarked in the *Stransham*-Ford Appeal decision:

> "When an appropriate case [not an urgent application as was the application by Stransham-Ford] comes before our courts the common law will no doubt evolve in the light of the considerations outlined there [principles already embedded in our common law and our constitutional rights] and the development in other countries."[1061]

The above cases indicate that the action of committing suicide is not a crime in South Africa, but assisting, aiding, abetting and/or conspiring with someone to commit suicide is. Where the accused is convicted of murder, the courts have a wide discretion in the common law to impose a sentence it deems fit. However after the advent of the Criminal Procedure Act, it has to be argued that there are "substantial and compelling factors" in terms of the Criminal Procedure Act[1062] which warrants a departure from the applicable minimum sentence, such as in the Davison case the minimum sentence had he been found guilty of murder, would have been life imprisonment.

In the *Estate Stransham-Ford* case the court confirmed that cessation of medical treatment which serves no curative, therapeutic or palliative purpose does not constitute a criminal offence by the physician. In such a case the disease itself will be considered to be the cause of death and not the cessation of medical treatment.

According to Dhai, McQuoid-Mason & Knapp van Bogaert when one interprets health care and values, it has to be borne in mind that a profession, such as the medical profession's moral position on an issue such as assisted suicide[1063] is based on the profession's current value system. The authors state that values and the ranking of

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[1060] DignitySA Press Release "Dignity South African joins court case in support of terminally ill patients" (18 September 2017).
[1061] *Minister of Justice and Correctional Services v Estate Late James Stransham-Ford* [2017] 1 All SA 354 (SCA) at para 101.
[1062] Section 51(3)(a) Criminal Procedure Act,105 of 1997.
[1063] My addition.

these can both persist and change over time and caution health care practitioners to remain mindful of their profession's values and that the health care policy makers and organisations should revisit these values from time to time.[1064]

In the Netherlands where a request for euthanasia is permissible in advance directives the Dutch Medical Association provide the following example of such a request:[1065]

Ik verzoek mijn arts om euthanasie uit te voeren als ik: *Ik besef dat het mogelijk is dat mijn euthanasieverzoek niet wordt uitgevoerd, ook al heb ik een schriftelijk euthanasieverzoek opgesteld en heb ik dit verschillende keren met mijn arts besproken.* *Naam: Handtekening: Datum:*

5.11 Palliative Care and Pain Relief

In all legal medical ethical treatment decisions, such as palliative care and the provision of pain relief, and whether a patient has to be hospitalised and a choice of a course of treatment to be administered or withheld, it has to be determined who can and should ultimately make the treatment decision. Would it be the first responders for example the ambulance paramedics, the doctor, the patient contemporaneously or through the use of a living will or an advance directive, or the whole health care team? According to

[1064] Dhai A, McQuoid-Mason D & Knapp van Bogaert D "Ethical concepts, theories and principles and their application to healthcare" in Dhai A & McQuoid-Mason D *Bioethics, Human Rights and Health Law: Principles and Practice* (2011) 6.

[1065] KNMG "Spreek op tijd over uw levenseinde" (2017) <https://www.knmg.nl/web/file?uuid=cc27dfa9-0997-420b-b5e7-a0af69d99b8f&owner=5c945405-d6ca-4deb-aa16-7af2088aa173&contentid=1220&elementid=147756> (accessed 16-09-2019).

Norval and Gwyther in the practice of palliative care it is not a straightforward answer and the whole health care team work together to consider the facts, the assumptions and ethical principles, debate the issues, come to a working decision and reassess the decision if appropriate. [1066]

In the *Stransham-Ford* decision the court said it is acceptable for a physician to administer treatment or medication to a patient without incurring any liability, while knowing full well that the patient's lifespan would be indeterminably shortened. It is therefore advisable that a clause emphasising the workings of the doctrine of double effect be inserted into a living will document.[1067]

5.12 Organ Donation

Organ donation allows a person to make a gift or donation of his or her organs and tissues to others once he or she has been declared dead. South Africa has specific organ donation laws. A person can donate organs for transplantation in a recipient, for scientific research or medical education. Organ donation can thus benefit others directly through the receipt of organ implants, or organ donation can benefit society as a whole through research and education.

The process to become an organ or tissue donor in South Africa is a relatively simple process. A potential organ donor can register online or call the Organ Donor Foundation's toll free telephone line or sign up online. An organ donor card will then be sent to the donor to fill in and carry in his or her wallet. The Organ Donation Foundation sends donors stickers for their Identity Documents and drivers' licenses as these documents are the first that emergency medical personnel normally look for in order to identify patients. The Organ Donor Foundation advocates that donors should have open discussions with their family members about their decisions. It is very important that an organ donor informs the family members of their intention, discusses the decision with

[1066] Norval D & Gwyther E "Ethical decisions in end-of-life care" 2003 *CME* 21 5 268.
[1067] See discussion on the doctrine of double effect in Chapter 5 para 5.10.4.

his or her family to inform them that he or she wants to donate organs and/or tissue after death and requests the family members to honour the patient's wishes should he or she die. In doing so, the family members will be more likely to give their required consent to the deceased's organ harvesting. Any person who is in good health and is clear of defined chronic diseases that might adversely affect the recipient, will be considered as a possible donor.[1068]

Countries have different systems of organ donation namely "opt in" or "opt out". Fourie explains the "doctrine of presumed consent" also known as the "opting out" system as "an organ procurement system under which individuals who have not during their lifetime raised an objection to organ donation, will upon death be presumed that they have no objection against the removal of their organs for transplantation purposes and in effect, give consent to the removal. A failure to indicate refusal would be considered an implicit statement of consent".[1069]

Etheredge, Penn and Watermeyer have examined the different proposed systems to increase organ donation in South Africa, using empirical ethics analysis. The study refers to the fact that the demand for organs in South Africa far exceeds the supply thereof. However, the fact that the high demand exceeds the supply, is not a uniquely South African phenomenon, but seen internationally. The researchers conclude that it would be best to maintain the soft opt-in policy, currently in place, in South Africa, but that the South African policy should be enhanced by a so-called "required transplant referral" to maximise donor numbers within an ethically and legally acceptable framework.[1070]

[1068] *The organ donor foundation of South Africa* <https://www.odf.org.za/> (accessed 1/7/2018).
[1069] Fourie EJ *An analysis of the doctrine of presumed consent and the principles of required response and required request in organ procurement* (2005) (LLM Dissertation) 26.
[1070] Etheredge H, Penn C & Watermeyer J "Opt-in or opt-out to increase organ donation in South Africa? Appraising proposed strategies using an empirical ethics analysis" (16 May 2017) <https://doi.org/10.1111/dewb.12154> Wiley online (accessed 17-07-2019).

The researchers found that the current soft opt-in system poses certain challenges such as to increase donor numbers within the current health care system, but note that the multiracial and multicultural nature of South African society has differing cultural and personal beliefs and practices on organ donation. The study indicated that there is a great deal of distrust of organ transplantations as people have varying levels of education and health literacy. The authors conclude that a soft opt-in system is most realistic for South Africa because its implementation does not require extensive public education campaigns at a national level, and it "does not threaten to further erode trust at a clinical level".

In the Netherlands a new organ donation bill was passed in parliament. In terms of the new bill organ donation will be an opt-out procedure. In terms of the new bill all Dutch adults become organ donors after death, unless they actively decide to opt out. It is said that the new act will come into operation on 1 July 2020.[1071]

The court stated in the *Soobramoney* case that:

> "We live in a society in which there are great disparities in wealth. Millions of people are living in deplorable conditions and in great poverty. There is a high level of unemployment, inadequate social security, and many do not have access to clean water or to adequate health services. These conditions already existed when the Constitution was adopted and a commitment to address them, and to transform our society into one in which there will be human dignity, freedom and equality, lies at the heart of our new constitutional order. For as long as these conditions continue to exist that aspiration will have a hollow ring".[1072]

[1071] Van der Aa E "Eerste Kamer akkoord met omstreden donorwet" *Eindhovensch Dagblad* 13 February 2018 <https://www.ed.nl/politiek/eerste-kamer-akkoord-met-omstreden-donorwet~a0bb915a/?_sp= 5616a039-4f9b-4f68-978d-0b25c0fcdaf6.1518768377676> (accessed 16-02-2018).

[1072] *Soobramoney v Minister of Health, KwaZulu-Natal* 1998 1 SA 765 (CC) par 8.

5.13 Helpful Documents

5.13.1 Values History

According to Dhai, McQuoid-Mason and Knapp van Bogaert "[t]he study of values and value systems is very complex". Values and value systems also differ according to the different roles people have to fulfil in society. The authors explain that "[e]ach of these different roles involves some degree of social and psychological interaction. However, they all share a common dimension – they all involve morality".[1073]

It is up to each person to make a personal value judgment which entails that each person must form his or her own judgement about value issues and value conflicts.[1074] Health care ethics requires that health care practitioners must "frame their personal and professional values differently".[1075] Health care professionals should not allow their personal values to override other health care considerations, because should their personal values prejudice the patient, the health care professionals can be held responsible for the breach of professional responsibility.[1076]

Different societies have developed different documents to help patients to formulate their wishes in terms of end of life decisions. The "values history" is one such document developed Dr David Doukas and Dr Laurence McCullough to supplement an advance directive.[1077] The theory behind the "values history" document is that patients are

[1073] Dhai A, McQuoid-Mason D & Knapp van Bogaert D "Ethical concepts, theories and principles and their application to healthcare" in Dhai A & McQuoid-Mason D *Bioethics, Human Rights and Health Law: Principles and Practice* (2011) 6.
[1074] Dhai A, McQuoid-Mason D & Knapp van Bogaert D "Ethical concepts, theories and principles and their application to healthcare" in Dhai A & McQuoid-Mason D *Bioethics, Human Rights and Health Law: Principles and Practice* (2011) 6.
[1075] Dhai A, McQuoid-Mason D & Knapp van Bogaert D "Ethical concepts, theories and principles and their application to healthcare" in Dhai A & McQuoid-Mason D *Bioethics, Human Rights and Health Law: Principles and Practice* (2011) 7.
[1076] Dhai A, McQuoid-Mason D & Knapp van Bogaert D "Ethical concepts, theories and principles and their application to healthcare" in Dhai A & McQuoid-Mason D *Bioethics, Human Rights and Health Law: Principles and Practice* (2011) 7.
[1077] The term was made famous by Dr Emund Pellegrino in the early 1980s to describe discussions between doctors and patients to ascertain the values that are important to the patient's healthcare

encouraged to think about their specific health care values and are encouraged to communicate the values that would be important to them in the event of terminal illness or should they become locked in a persistent vegetative state. The "values history" contains advance directives statements which the patient has to think about. The individual can complete the document with the statements and be assured that the document will clearly state his or her wishes to family members and healthcare personnel.[1078]

The document allows the person to specify his or her rejection or acceptance of different therapies and his or her willingness to partake in a trial of intervention. A trial of intervention means that a specific therapy is carried out for a specific period or as long as it takes to determine that a benefit will be gained through the therapy or that the therapy is futile.

5.13.2 Dignity SA: Advance Directive/Living Will Planning Guide

The South African society Dignity SA has produced a similar document namely "Advance Directive Planning Guide".[1079] DignitySA's Advance Directive Planning Guide states that when planning your advance directive, a person should first of all consider his or her own personal values and beliefs. The Guide also contains considerations with reference to the appointment of a medical proxy and how to approach a discussion with your chosen medical proxy, family members and medical doctor. The Guide contains a list of definitions of medical terminology applicable to this field for example persistent vegetative state, terminal illness and palliative care. The Guide contains a list of helpful frequently asked questions and a fact sheet to inform the reader of the current legal position in South Africa.

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decisions. Doukas DJ & Reichel W *Planning for uncertainty: A guide to Living Wills and other Advance Directives for Health Care* (1993) 67.

[1078] Doukas DJ & Reichel W *Planning for uncertainty: A guide to Living Wills and other Advance Directives for Health Care* (1993) 67 – 68.

[1079] Dignity SA "Advance Directive Planning Guide" <http://www.dignitysa.org/blog/advance-directive/> (accessed 13-2-2018).

5.13.3 Five Wishes

Aging with Dying, Florida has developed the "Five Wishes" advance directive which has been drafted to adhere to legal and medical specifications of different states in America. According to their website:

> "Written in user-friendly lay language, *Five Wishes* was the first advance directive to address personal, emotional, and spiritual issues in addition to meeting medical and legal criteria. Because the document is based on what is important to people, it has been widely embraced by families, community groups, faith communities, and medical and legal providers."[1080]

The Five Wishes directive is said to be legally enforceable in the listed 43 States of America. The concept of the five wishes document is of universal applicability and thus useful to anybody who wants to draft a living will or advance directive. The five wishes directive can be downloaded from Aging with Dignity's website.[1081] The five wishes of the Five Wishes directive are summarised as follows:

1. Who do you as the future patient trust to make decisions for you?
2. What are the types of medical treatment you would want and not want?
3. What is most important for your comfort and dignity?
4. What important spiritual or faith traditions should be remembered?
5. What would you like your loved ones and healthcare providers to know about you?[1082]

[1080] Aging with Dignity "Who are we" <https://fivewishes.org/five-wishes/who-we-are/about-us/our-history-and-mission> (accessed 18-08-2019).
[1081] Aging with Dignity "Preview of a Sample of Five Wishes" <https://fivewishes.org/five-wishes/individuals-families/individuals-and-families/advance-care-planning> (accessed 18-08-2019).
[1082] Aging with Dignity "Focusing on What Matters Most" <https://fivewishes.org/five-wishes/individuals-families/individuals-and-families/advance-care-planning> (accessed 18-08-2019).

5.14 Draft Examples of Living Wills and Advance Directives

5.14.1 Carstens and Pearmain: "Living Will"

" **'EXAMPLE ONLY'***[1083]

LIVING WILL

1. I, (name)……..
of (address)……...
Make this Living Will after careful consideration and while in sound mind, to state my wishes in case I become unable to communicate, and cannot take part in decisions about my medical care.
2. I do not wish to be kept alive by medical treatment, if I have a physical illness with no likelihood of recovery, and/or if my mental functions become permanently impaired, and/or if I become permanently unconscious with no chance of regaining consciousness.
3. I request that medical treatment be kept to the minimum needed to keep me comfortable and free from pain, even if this should hasten the moment of death. I expressly direct that I be given whatever quantity of drugs required to keep me free from pain or distress even if the moment of death is hastened thereby. I expressly do not consent to be kept alive artificially, including (but not confined to) performing a gastrostomy, inserting a nasogastric tube or employing any form of mechanical ventilation, and/or to provide any form of tube feeding.
4. I have informed this doctor/clinic of this Living Will.
   (name)…….
   (address)…….
   (contact telephone for doctor/clinic)…..…….

[1083] Carstens PA & Pearmain D *Foundational Principles of SA Medical Law* (2007) Annexure V Source: American Medical Association Medicolegal Forms with Legal Analysis (1991).

5. I give consent to any person to apply for a court order to ensure that this Living Will is followed if any medical, health authority or institution, and or family member or partner refuses to follow my instructions.

6.* I wish to be kept alive for as long as it is reasonable to enable the following person(s) to be with me before I die, even if this means temporarily going against the wishes stated earlier in this Living Will.

(name)…….

of (address) ……...

(telephone numbers)……

7. I appoint this person

(name)…….

of (address)……

(telephone numbers)…….

to take part in decisions about my medical care on my behalf, and to represent my views about them, if I am unable to do so. I wish to be consulted about or involved in those decisions. Further, I wish those caring for me to respect the views expressed on my behalf unless they are in conflict with my wishes in this Living Will.

8. This document remains effective until I make it clear, while in sound mind, that my wishes have changed.

9. This declaration is signed and dated by me and confirmed by the two witnesses below.

Signed	Date
Witnesses:	
Signature:	Signature:
Name:	Name:
Address:	Address:

* May be omitted. If necessary delete, date and sign in full.

* NOTE DISCLAIMER AT THE END OF THE INDEX"[1084]

5.14.2 Carstens and Pearmain: Health Care Proxy

"EXAMPLE ONLY"*[1085]

HEALTH CARE PROXY

I appoint as my proxy decision-maker(s):

……

Name and Address

and (optional)

……

Name and Address

I direct my proxy to make health-care decisions based on his/her assessment of my personal wishes. If my personal desires are unknown, my proxy is to make health-care decisions based on his/her best guess as to my wishes. My proxy shall have the authority to make all health-care decisions for me, including decisions about life-sustaining treatment, if I am unable to make them myself. My proxy's authority becomes effective if my attending physician determines in writing that I lack the capacity to make or to communicate health-care decisions. My proxy is then to have the same authority to make health-care decisions as I would if I had the capacity to make them, EXCEPT (List the limitation, if any, you wish to place on your proxy's authority):

[1084] Disclaimer: "The authors and publishers of this book wish to emphasise the fact that the foregoing annexures (as contained on the CD-Rom), specifically the examples of various forms and precedents are solely offered as practical generic examples/illustrations of the practical application of medical law. These examples are in no way to be regarded as all encompassing forms/precedents and are published for general information and are not intended as legal advice. As every situation depends on its own facts and circumstances, the purpose of the annexures is to provide practical guidance only. The examples of forms/precedents provided are therefore illustrative only. They lack specific content and substance and should under no circumstances be used as they stand. The authors and publishers therefore accept no responsibility for any consequences or damages of whatever nature flowing/arising from/brought about by the use of and/or reliance on the forms/precedents contained in the foregoing annexures by anyone."

[1085] Carstens PA & Pearmain D *Foundational Principles of SA Medical Law* (2007) Annexure Q Source: American Medical Association *Medicolegal Forms with Legal Analysis* (1991).

I wish my written preference to be applied as exactly as possible/with flexibility according to my proxy's judgment. (Delete as appropriate)

Should there be any disagreement between the wishes I have indicated in this document and the decisions favoured by my above-named proxy, I wish my proxy to have authority over my written statements/I wish my written statements to bind my proxy. (Delete as appropriate)

If I have appointed more than one proxy and if there is disagreement between their wishes…… shall have final authority.

Signed:

……

Signature Printed Name

……...

Address Date

Witness:

……

Signature Printed Name

……

Address Date

Witness:

……

Signature Printed Name

……...

Address Date

Physician (optional)

I am…….. 's physician. I have seen this advance care

document and have had an opportunity to discuss his/her preferences regarding medical interventions at the end of life. If …… becomes incompetent, I understand that it is my duty to interpret and implement the preferences contained in this document in order to fulfil his/her wishes.

Signed:

……..

Signature Printed Name

……..

Address Date

* NOTE DISCLAIMER AT THE END OF THE INDEX

5.14.3 National Health Amendment Bill, 2019: "Guideline for a Living Will"[1086]

"SCHEDULE 3

GUIDELINE FOR A LIVING WILL

(*Section 7B*)

I, ……..(full name),

in making this Living Will, wish to confirm that I

- am 18 years or older;
- am of sound mind;
- act of my own free will, free from duress induced by others; and
- have carefully considered my own values, beliefs and preferences, as well as misfortunes of body and/or mind that may befall me.

Hence, should I, as a result of illness, injury or any other trauma, at a future date,

[1086] National Health Amendment Bill, 2019 Schedule 3 to clause 7(B). This specific draft can also be downloaded from DignitySA's website "Download your living will" <https://dignitysouthafrica.org/ advance-directive> (accessed 15-08-2019).

- develop a terminal and incurable medical condition; or
- become permanently vegetative; or
- become completely and irreversibly unconscious,

and, as a consequence, no longer possess the requisite rationality or competence to have or communicate my health care decisions,

I grant authority to and authorise any medical professional and/or medical facility and/or other carer to execute this Living Will, thereby allowing me to die a natural death by refraining from keeping me alive by artificial means, or by potentially life-sustaining medical intervention, treatment or procedure, such as:

- artificial nutrition;
- artificial hydration;
- dialysis;
- any medication or drug, including antibiotics, administered through any method, including an IV tube; or
- life support of any kind.

[*The maker of a Living Will is free to insert a clause instructing an attending or treating medical doctor/health care professional, or any other person, not to discontinue a specific form of life-sustaining treatment, for example, artificial hydration.*]

In addition, I authorise any attending medical professional and/or medical facility and/or other carer to administer to me comfort or palliative care, specifically adequate medication to alleviate my pain and suffering, even though it might hasten my natural death as a secondary consequence.

Moreover, I give permission for any of my organs or tissue to be donated for legitimate medical or scientific purposes. [*This clause may be excluded.]*

MAKER of this Living Will

Name (print in full) . . . . . .

Signed at (name of place) . . . . . .

Identity or passport number . . . . . .

Signature . . . . . Date . . . . . .

WITNESS 1 to the signing of this Living Will

I declare that I have witnessed the signing of this Living Will by (i) the maker of the Living Will and (ii) witness 2.

Name (print in full) . . . . . .

ID or passport number . . . . . .

Relationship to the maker . . . . . .

Telephone number . . . . . .

Email address . . . . . .

Full residential address . . . . . .

Signature . . . . . Date . . . . . .

WITNESS 2 to the signing of this Living Will

I declare that I have witnessed the signing of this Living Will by (i) the maker of the Living Will and (ii) witness 1.

Name (print in full) . . . . . .

ID or passport number . . . . . .

Relationship to the maker . . . . . .

Contact telephone number . . . . . .

Email address . . . . . .

Full residential address . . . . . .

Signature . . . . . Date . . . . . ."

5.14.4 National Health Amendment Bill, 2019: "Guideline for durable power of attorney for health care"[1087]

''SCHEDULE 2

GUIDELINE FOR A DURABLE POWER OF ATTORNEY FOR HEALTH CARE

(*Section 7A*)

I,……..(full name),

in granting this Durable Power of Attorney for Health Care, wish to confirm that I

- am 18 years or older;
- am of sound mind;
- act of my own free will, free from duress induced by others; and
- have carefully considered my own values, beliefs and preferences, as well as misfortunes of body and/or mind that may befall me.

Hence, should I, as a result of illness, injury or any other trauma, at a future date, develop any condition as a consequence of which I lack the requisite competence to have or communicate any rational preferences regarding my future health care,

I wish to appoint…….(full name)

as my agent (*proxy*) health care decision-maker, mandating him/her to act as my substitute for any and all of my health care and medical decisions, and instructing any person or institution to act on the directives of this duly appointed health care agent.

Should my first choice as health care agent be unable to assume this responsibility, I wish to appoint

……..(full name)

[1087] National Health Amendment Bill, 2019 Schedule 2 to clause 7(A). This specific draft can also be downloaded from DignitySA's website "Download your living will" <https://dignitysouthafrica.org/ advance-directive> (accessed 15-08-2019).

as my alternative agent (*proxy*) health care decision-maker, mandating him/her to act as my substitute for any and all of my health care and medical decisions, and instructing any person or institution to act on the directives of this duly appointed health care agent.

I understand that this Durable Power of Attorney for Health Care mandates my health care agent to make health care and medical decisions on my behalf for the duration of my biological life, thus enduring while I am no longer competent to revoke it. Should I, however, regain the requisite competence, I understand that I would have the authority to revoke this health care mandate.

In making health care and medical decisions on my behalf, my health care agent should give due recognition to my known values, beliefs, principles and personal preferences. Should it be impossible or difficult to know the practical implications of these considerations in particular circumstances, my health care agent should act in my objectively determined best interest.

In particular, I authorise my health care agent (proxy) decision-maker to make any and all of my health care and medical decisions on my behalf, that is, any and all decisions I would have made while still competent.

In this mandate to my health care agent decision-maker, I specifically include decision-making directives that would be routinely included in a Living Will, that is, directives relating to refraining from life-sustaining medication, treatment or procedures that would otherwise prolong life, thus impeding a natural death. [*This clause may be excluded.*]
In addition, I mandate my health care agent to make decisions on my behalf regarding the donation of my organs or tissue for any legitimate medical or scientific purpose. [*This clause may be excluded.*]

[*The grantor/maker of a Durable Power of Attorney for Health Care is free to issue specific instructions or directives to his/her health care agent about any medical intervention that the grantor/maker chooses to include in or exclude from the mandate.*]

GRANTOR/MAKER of health care mandate/proxy

Name (print in full) . . . . . .

Signed at (name of place) . . . . . .

Identity or passport number . . . . . .

Signature . . . . . Date . . . . . .

WITNESS 1 to the signing of this Durable Power of Attorney for Health Care

I declare that I have witnessed the signing of this Durable Power of Attorney for Health Care by (i) its grantor/maker and (ii) witness 2.

Name (print in full) …….

ID or passport number …….

Relationship to the maker ……..

Contact telephone number …….

Email address …….

Full residential address ……..

Signature . . . . . Date . . . . . .

WITNESS 2 to the signing of this Durable Power of Attorney for Health Care

I declare that I have witnessed the signing of this Durable Power of Attorney for Health Care by (i) its grantor/maker and (ii) witness 1.

Name (print in full) …….

ID or passport number …….

Relationship to the maker ……..

Contact telephone number …….

Email address …….

Full residential address ……..

Signature ……. Date ……..”

5.14.5 South African Medical Association: "Living Will"[1088]

LIVING WILL

TO MY FAMILY AND MY PHYSICIAN:

I,

NAME AND SURNAME_____ (ID NUMBER),

the undersigned, presently residing at

ADDRESS_____,

after careful consideration, make the following declaration, which I call my Living Will:

1. This Living Will in no way revokes nor does it change any Will or Testamentary disposition as made by me at a previous occasion.

2. In this Living Will, unless an intention to the contrary appears clearly and concisely the following words carry the meaning as stated: -

- "Doctors" refer to one or more medical practitioners who may be requested to provide me with a prognosis from time to time, depending on my condition and clinical status at any given moment during my treatment and/or hospitalization

- "Secondary support system" refer to any artificial and/or mechanical life support system and/or medication/drugs to the same effect

[1088] South African Medical Association "Guidelines with regard to living wills" (2012) <https://www.samedical.org/images/attachments/guidelines-with-regard-to-living-wills-2012.pdf> (accessed 15-08-2019).

If the time comes when I can no longer take part in decisions for my own future, let this declaration stand as my directive.

If there is no reasonable prospect of my recovery from physical illness or impairment expected to cause me severe distress or to render me incapable of rational existence, I do **not** give my consent to be kept alive by means of a Secondary support system, including by way of a pacemaker.

I also do **not** give my consent to any form of tube-feeding when I am dying; and I request that I receive whatever quantity of drugs and intravenous fluids as may be required to keep me free from pain or distress even if the moment of death is hastened.

This declaration is signed and dated by me in the presence of the under mentioned two witnesses present at the same time who at my request and in my presence and in the presence of each other have hereunto subscribed their names as witnesses.

Dated at _____ on this the _____ day of _____.

Witnesses (Not to be members of one's family or beneficiaries in the estate)

Signature _____ Signature _____

Name _____ Name _____

Address _____ Address _____

5.14.6 South African Living Will Society: “Living Will”

Living Will
“If the time comes when I can no longer take part in decisions for my own future let this declaration stand as the testament to my wishes. If there is no reasonable prospect of my recovery from physical illness or impairment expected to cause me severe distress or to render me incapable of rational existence, I request that I be allowed to die and not be kept alive by artificial means and that I receive whatever quantity of drugs may be required to keep me free from pain or distress even if the moment of death is hastened.”[1089]

5.15 Conclusions

In this chapter the drafting of living wills and advance directives was discussed. Specific circumstances that can or cannot be included in a living will or advance directive were discussed. Draft examples of living wills and advance directives including a do-not-resuscitate order and durable powers of attorney were included. The researcher includes her version of a combined living will and advance directive document in chapter 6 paragraph 6.2.7. In this chapter the various draft legislation documents and proposals, as well as opinions from critics were discussed. The importance of legislation on living wills and advance directives was discussed. All these sources have in common that legal certainty needs to be obtained. The researcher submits that detailed legislation and supporting regulations need to be enacted for the legal enforcement of living wills in South Africa

[1089] The South African Living Will Society is no longer in existence. This version appeared in the South African Law Commission’s Report “Euthanasia and the Artificial Preservation of Life” “Project 86” (1997) 156 and in Strauss SA Doctor, patient and the law (1991) 344.

CHAPTER 6:
CONCLUSIONS

Outline

"*Vragen van leven en dood maken onslosmakelijk deel uit van het medische beroep. De arts heeft door zijn beroepskeuze de opdracht aanvaard, mensen die ziek zijn of oud, die pijn of ander ongemak lijden te helpen. Komt zijn patient aan het eind van de levensweg, dan moet de arts zijn houding bepalen ten opzichte van diens sterven en dood. Hij heeft dan de feitelijke macht de dood te laat komen, de dood uit te stellen, de dood te vervroegen. Wat hij ook kiest, steeds gaat hij om met de dood van zijn patient. Dat is altijd zo geweest en is ook niet anders denkbaar."*[1090]

6.1 Research Question

This thesis answers the research question posed in chapter 1 paragraph 1.3. The research question as formulated in chapter 1 was worded as follows: what is the current legal status of living wills in South Africa and how can legal enforcement thereof be achieved.[1091]

6.2 Research Aims

The purpose of the thesis was to investigate the current legal position regarding living wills in South Africa and to provide a foundation for the possible development of the South African legal system to give effect to the rights and wishes of patients who issued instructions by means of living wills.[1092]

6.2.1 Research Aim 1

The first research aim was to provide an historico-legal background to and an overview of living wills in South Africa. This was achieved by considering the relevant hypotheses underlying living wills in South Africa such as patient autonomy, the question of sanctity of life versus quality of life as well as the concepts of *beneficence* and *non-maleficence*.

[1090] Enschedé Ch J *De Arts en de dood: sterven en recht* (1985) 11.
[1091] See Chapter 1 para 1.3.
[1092] Research aims are set out in Chapter 1 para 1.4.

Justice and socio-economic factors were considered with reference to the ethical guidelines of the Health Professions Council of South Africa, the South African Medical Association and international codes of health care ethics. The Draft Bill on End of Life Decisions and the National Health Amendment Bill were also discussed. In these discussions, the relevant case law was considered.

6.2.2 Research Aim 2

The second research aim was to analyse the framework of constitutional rights relevant to the context of end-of-life decisions. This research aim was mainly addressed in chapter 2 of the thesis, but is also discussed in relevant sections throughout the thesis. The focus was on the following selected human rights: the right to life, the right to dignity, the right to privacy, the right to equality, the right to security of the person which includes bodily and psychological integrity, the right to freedom of religion, belief and opinion and the right to access to health care. It was shown that the right to life is inextricably connected to the right to dignity. The right to dignity in life extends from the beginning of life to the end of life and therefore the rights to life and dignity are crucial in the realm of end-of-life decisions and living wills. Fabricius J, in the *Stransham-Ford*[1093] decision agreed with the applicant's contention that the right to die with dignity is regarded as a fundamental human right. Since the rights to life and dignity are "entwined" the right to life incorporates more than mere physical existence, but an existence consonant with human dignity. So too is the right to end life with dignity. The hypothesis that a right to life should include the right to death was debated.[1094]

[1093] *Stransham-Ford v Minister of Justice and Correctional Services and Others* [2015] 3 All SA 109 (GP). The judgment was overturned by the *Minister of Justice and Correctional Services v Estate Late James Stransham-Ford* [2017] 1 All SA 354 (SCA) decision. See paras 5.10.5.3 and 5.10.5.4.
[1094] See discussion on the right to dignity in para 2.3.3.

6.2.3 Research Aim 3

The third research aim was to analyse current draft legislation on living wills in South Africa. The following were discussed: the National Health Act, the South African Law Commission's Draft Bill on End of Life Decisions and the National Health Amendment Bill (Private Member's Bill), as well as the ethical guidelines that were created in an attempt to fill the legal uncertainties. This aim was addressed in chapters 1, 3 and 5 of the thesis.

6.2.4 Research Aim 4

The fourth research aim was to analyse how the current legal framework in South Africa relates to medical, ethical, moral and philosophical issues. This aim was also addressed in chapters 3 and 5 of the thesis. In these chapters issues on and guidelines for drafting living wills in South Africa were analysed.

The SA Law Commission's Report referred to the fact that medical practitioners should be obliged to give effect to patients' explicit statements to for instance refuse specified treatment in living wills, and that they could expose themselves to liability if they were to disregard such explicit instructions.[1095] The South African Law Commission's Report however cited a number of problem areas that will need to be addressed for the development of a legal framework for living wills:

6.2.4.1 Explicit Instructions

The need for explicit and clear instructions contained in living wills was articulated. As discussed in chapters 3 and 5, instructions cannot be too vague or too narrow and the specific medical circumstances that the incompetent patient finds him- or herself in,

[1095] South African Law Commission "Euthanasia and the Artificial Preservation of Life" "Project 86" (1997) 182.

must be mentioned in the living will, otherwise the living will can be found to be not applicable to the situation.[1096]

6.2.4.2 Doctor-Patient Relationship

The SA Law Commission's Report further indicates that in South Africa "The reliance of patients on their physicians may be misplaced due to physicians' lack of knowledge about the documents' legal reliability and physician anxiety relating to potential civil and criminal liability".[1097] It is the researcher's submission that doctors will need paralegal training to equip them with the necessary knowledge of the law and its implementation.

Dörfling foresees a number of problems if advance directives are not regulated by statute, for the moral and ethical codes of health care personnel may compel doctors to act contrary to the instructions in the living will. The uncertainty and fear of possible prosecution may for instance influence health care personnel to ignore medical instructions contained in a living will, and furthermore the fact that there is currently no criminal sanction for the tampering or destruction or concealment of a living will, can be problematic.[1098] Once living wills form part of a patient's medical record, it will be an offence for any third parties to tamper, destroy or conceal such documents.[1099]

The doctor-patient relationship and related doctor-patient communication with reference to living wills involve that a patient needs to be informed of his or her illness and treatment options to be able to consent (informed consent) or refuse (informed refusal) to the specific treatment.[1100] In circumstances where a patient is not mentally competent

[1096] See Chapter 5 para 5.3.3.
[1097] South African Law Commission "Euthanasia and the Artificial Preservation of Life" "Project 86" (1997) 182.
[1098] Dörfling DF *Genadedood in die Strafreg – 'n regsfilosofiese en regsvergelykende perspektief* (1991) 195. See S 102(1)(a) Administration of Estates Act, 66 of 1965 which states that anyone who "steals or wilfully destroys, conceals, falsifies or damages any document purporting to be a will" is acting unlawfully and liable upon conviction to a fine or a period of imprisonment. A similar section must be included in future legislation on living wills.
[1099] See Chapter 5 para 5.3.4.
[1100] See Chapter 3 para 3.4.

to express his or her view, and advance directives and living wills are legally entrenched, the advance directive or living will must be followed. If a proxy directive was executed, the proxy as the legally appointed medical representative's decision must be followed. Where there is no advance directive or proxy directive, the National Health Act states that a patient's family members in hierarchical order can be appointed as the medical proxy, unless the patient did not want a specific person as proxy, then that person is excluded from the hierarchy. A court should also be able to order that a specific person could be appointed as a person's health care proxy. Where there is no indication of the patient's wishes, and no family members to convey the patient's wishes, then the doctor must follow the "doctor knows best approach". There appears to be a trend worldwide to move away from medical paternalism to an acceptance and greater support for patient autonomy. A doctor should, however, be able to override a medical proxy's instructions in certain circumstances, for example where the proxy has a self-interest in the matter such as an inheritance and not acting in the best interests of the patient and/or not adhering to the patient's wishes.

It is further advised that when it is alleged that there is a living will of which the validity and applicability cannot be ascertained with reasonably certainty or it is alleged that there is a durable power of attorney in existence and the health care proxy is not readily available, then emergency care must ensue until such time as the applicability and validity of the living will and/or the appointment and instructions from the proxy can be obtained.

At the very least advance directives and living wills serve to help doctors and patients to talk about treatment options and about death. The living will allows patients the opportunity to voice their concerns instructions in the form of consent and refusal of future medical treatments. In a country such as South Africa where there may be patients and doctors who are not able to communicate in their home language or in a language in which they are fluent, an infrastructure should be provided such as translation by a speaker of the language of communication, for example translators,

family members or other health personnel need to be brought in to help with translation. It is imperative that the patient understands his or her options in order to grant informed consent. The language of a living will should not be confusing and unduly complicated as a result of medical jargon so as to enable the patient to provide clear instructions while competent, for example on admission to a health care facility.

6.2.4.3 Informed Consent: An Ethical Issue

In chapter 3 the researcher referred to the National Health Act[1101] in her discussion of the current legal position regarding living wills in South Africa. The principle of informed consent was examined and the ethical guidelines provided by professional bodies such as the HPCSA and SAMA were considered.[1102] Relevant case law[1103] was cited and draft legislation evaluated (The Draft Bill on End of Life Decisions[1104] and the National Health Amendment Bill[1105]).

6.2.4.4 Drafting Issues: Explicit Directives for Particular Circumstances

Chapter 5 focused on the drafting of living wills and the current status of the legal enforceability and applicability of living wills in South Africa with reference to particular circumstances. The particular circumstances referred to included emergency situations and do not resuscitate orders, persistent vegetative states, dementia, cessation of artificial feeding and hydration and pregnancy. The current situation as regards euthanasia and assisted suicide was investigated. The importance of a doctor's duty of palliative care and pain relief was underlined and the practice of organ donation was included. Drafting guidelines were provided and *pro forma* examples of living wills were

[1101] National Health Act, 61 of 2003.
[1102] See Chapter 3 para 3.4 for the discussion on informed consent. See para 3.5 of HPCSA and SAMA guidelines.
[1103] See case law in 3.6.1.
[1104] See Chapter 3 para 3.7.1 and Chapter 5 para 5.3.
[1105] See Chapter 3 para 3.7.2 and Chapter 5 para 5.3.

included. The fact that a living will needs to be individualised with specific end-of-life care instructions for a particular patient was emphasised.

The researcher cited several examples of living wills and advance directives in chapter 5. It is the researcher's submission that the living will and advance directive must be combined in a single document.[1106]

6.2.5 Research Aim 5

The fifth research aim was to analyse and compare the law on living wills in the three selected countries. Chapter 4 dealt with the legal position of living wills, advance directives and end-of-life planning in the Netherlands, England and Canada.

6.2.5.1 Living Wills and Advance Directives in the Netherlands, Canada and England

In this thesis the differences in the legal frameworks in the three chosen jurisdictions namely the Netherlands, Canada and England, as well as the problematic aspects concerning the law and the applicability of the law in practice, were shown. The underlying legal frameworks were considered to see how living wills and other types of advance directives function in legal and medical practice in those jurisdictions. All three jurisdictions have varying terminology and interpretation and enforceability problems as far as living will documents are concerned. All three jurisdictions are currently attempting to improve the legal situation. It was shown that the use of advance directives strengthens patient autonomy. However, the issues of informed consent and patient autonomy versus medical paternalism and the best interests of the patient remain problematic.

The comparative legal study indicated that all three countries investigated are currently still grappling with end-of-life decisions in the law and practice. The fact that legislation

[1106] See Chapter 1 para 1.1.2 discussion and Chapter 6 para 6.2.7 draft example.

exists in some of these countries does not mean that advance directives and living wills are seamlessly enforced. Regulations, as well as codes of practice or protocols, need ongoing development and need to be sustained to aid the enforceability of living wills. The legal enforcement of living wills further increases the administrative load of doctors and health care institutions such as hospitals to obtain, verify the enforce the living will after the relevant parties such as family members have been informed of the doctor's intention to enforce the document.

6.2.5.1.1 What can we learn from the Netherlands?[1107]

In the Netherlands the practice of assisted suicide/euthanasia is well-established. It is even possible to issue a request for euthanasia in an advance directive which is specifically named a euthanasia directive. However, these euthanasia directives are of little practical force if the patient is no longer conscious or mentally competent to confirm his or her request.[1108] The Netherlands has a legal framework for different advance directives (*wilsverklaringe*) and living wills (*levenstestamente*).[1109] *Levenstestamente*, must be drafted by notaries and are kept on a national register and *wilsverklaringe* can be drafted by an individual, forms can be obtained from the NVVE and the NVVE will keep the *wilsverklaringe* of their members on their database for easy access. Should South Africa obtain legal recognition of living wills, one single reliable, efficient, easily accessible and consolidated database will need to be created of which the legal functions and oversight will have to be regulated to ensure the necessary patient confidentiality.

6.2.5.1.2 What can we learn from England?[1110]

In England "advance decisions" are drafted in terms of the Mental Capacity Act.[1111] The

[1107] See Chapter 4 para 4.3.
[1108] See van Delden in Chapter 4 para 4.3.1.2.2.
[1109] See Chapter 4 para 4.3.1.
[1110] See Chapter 4 para 4.4.
[1111] Mental Capacity Act, 2005.

presumption of capacity contained in said Act will be an important aspect to include in South Africa's legislation. To aid the legal enforcement of the Mental Capacity Act the Mental Capacity Act Code of Practice,[1112] Office of the Public Guardian and the recent National Mental Capacity Forum were created. These additional resources are vital to the success of the legislation. It is no use having legislation which cannot be implemented effectively and South Africa should learn from England in this respect.

6.2.5.1.3 What can we learn from Canada?[1113]

In almost all the provinces and territories of Canada advance directives are legally recognised. There is no federal law in Canada on advance directives, therefore terminology differs among the many jurisdictions. Different validity and enforceability requirements and issues exist. In South Africa an attempt should be made to obtain national legislation on living wills. In Canada, after the landmark *Carter*[1114] decision in which physician assisted suicide was decriminalised, Bill C-14 was promulgated by the Canadian Federal Government. There are many critiques that the ambit of Bill C-14 is too narrow – much narrower than the Supreme Court of Canada envisaged. If South Africa considers decriminalising physician assisted suicide, the *Carter* decision and the Canadian Parliament's Act should be analysed. The ongoing and upcoming Constitutional challenges to Bill C-14's ambit should also be carefully considered.

6.2.6 Problems with Terminology and Drafting

The first problematic aspect that the researcher came across was the fact that inconsistent terminology was used with reference to living wills or advance directives. This was not only the case in the South African legal system, but also internationally.[1115] The researcher proposes that in South Africa the Advance Directive and Living Will

[1112] Mental Capacity Act Code of Practice, 2005.
[1113] See Chapter 4 para 4.5.
[1114] See *Carter v Canada* 2015 SCC 5 in para 4.5.5.2.
[1115] See Chapter 1 para 1.1.2 & Chapter 4 paras 4.3.1, 4.4.1 & 4.5.1

documents be combined into one all-encompassing document.[1116] This document should have only one heading "Living Will" to aid the terminology problem. Such a document could be drafted to include detail about future medical treatment, for example emergency situations, the circumstances in which do not resuscitate orders should be implemented, dementia, artificial feeding and hydration and after death instructions with reference to organ donation and burial, cremation etc. This will also solve the dilemma of different documents having different meanings and applicability in different scenarios. The document should have clear and distinct headings such as "Emergency Situations" so that health care personnel can easily find the relevant sections and clauses. The document could contain clear instructions on specific important matters and could contain a wish list for other less important matters. Of course the patient's wishes will not always be met, for example wishes for future medical and financial circumstances that are not realistic, cannot be met. The patient could for instance request the family to place him or her in a specific care facility, but should there not be room or should it not be financially viable, the family and/or appointed decision maker could deviate from this wish. Clear instructions could include all the specific circumstances mentioned in chapter 5 as far as they are lawful instructions such as: do not resuscitate orders, do not commence artificial feeding and hydration orders or the appointment of a health care proxy. Since euthanasia and assisted suicide are unlawful at this point in time in South Africa, a request for euthanasia or assisted suicide cannot be included. Should the legal position change in future, such a clause could easily be inserted. In circumstances where the living will instructions involve the availability of medical treatment such as dialysis machines, such instructions could only be executed if the necessary equipment should be available.[1117]

The following document has been formulated by the researcher to serve as a possible example of a combined living will and advance directive document. Please note that this document does not constitute legal and medical advice, but that it has been formulated

[1116] See Chapter 1 para 1.1.2.
[1117] See discussion on the right to access to health care in para 2.3.8 and *Soobramoney v Minister of Health, KwaZulu-Natal* 1998 (1) SA 765 (CC).

as an illustrative example which has to be adapted to a person's personal and medical circumstances.

6.2.7 Living Will Example

The researcher's example of a combined living will and advance directive document:

LIVING WILL

I the undersigned
Title:
Full names:
Identity Number or Passport Number:
Age:
Domicilium:
and
Residence:
hereby confirm that I am of sound mind and make this my living will. I have carefully considered all the below clauses and hereby instruct that my wishes and instructions contained herein be followed, once I am mentally incompetent or unable to communicate and cannot partake in my health care decisions.

Appointment of health care proxy

1. I hereby appoint:
Full names:
Identity Number or Passport Number:
Address:
Telephone numbers:
Alternative telephone numbers:
to act as my health care proxy, to take part in decisions about my medical care on my behalf, and to represent my views, beliefs and desires about the medical care that I

would want, if I am unable to do so. My proxy shall have the authority to make all health care decisions for me:
life-sustaining treatment,
(list your specific treatments)

The proxy shall not have the authority to make the following treatment decisions for me:
life-sustaining treatment,
(*list your specific treatments*)

(*Add a second alternative proxy if so desired. Then state which proxy has the overriding/final say*)

The proxy's authority becomes effective upon the treating doctor's determination, ideally confirmed by another doctor, that I lack the mental capacity to make or to communicate my own health care decisions.

Should any disagreement arise between the wishes I have indicated in this living will document and the decisions made by my above-mentioned proxy, I request that my proxy has the authority to override my written statements/ wishes contained elsewhere in this living will.[1118]

Refusal of medical treatment

2. I do not wish to be kept alive by artificial medical treatment, including (but not confined to) performing a gastrostomy, inserting a nasogastric tube or employing any form of mechanical ventilation, and/or to provide any form of tube feeding if I have a physical illness with no likelihood of recovery, and/or if my mental functions become permanently impaired, and/or if I become permanently unconscious with no chance of regaining consciousness.

[1118]See discussion of the National Health Amendment Bill 2019 (Private Member's Bill) and overriding of patients' instructions contained in living will documents at p147.

3. (Insert *Do-Not-Resuscitate Order* if required)

Request for medical treatment

4. I request that medical treatment be kept to the minimum needed to keep me comfortable and free from pain, even if this should hasten the moment of death. I expressly direct that I be given whatever quantity of drugs required to keep me free from pain or distress even if the moment of death is hastened thereby. (The doctrine of double effect).

5. I wish to be kept alive for as long as it is reasonable to enable the following person(s) to be with me before I die, even if this means temporarily going against the wishes stated earlier in this Living Will.

Third party knowledge

6. I have informed my family doctor/clinic of this Living Will:

Name:

Address:

Contact telephone numbers:

Consent

7. I consent to the living will forming part of my medical record.

8. I waive the right to patient-doctor confidentiality of my medical record as far as it pertains to communicating the contents of my living will to my health care team, my family members and other parties who may have an interest in my illness/condition and the treatment thereof.

Doctor's release

9. Any medical practitioner and health care worker who adheres to the instructions contained herein, shall not be held liable for acting on my instructions, if done with reasonable skill and care.

Consent to legal proceedings

10. I give consent to any person to apply for a court order to ensure that this Living Will is followed if any medical, health authority or institution, and or family member or partner refuses to follow my instructions.

Organ donation

11. I feel very strongly that my organs may be donated. Even though I did not consent to life support, I do consent to my body temporarily being put on life support in order to retain the health of my organs to ensure optimal organ harvesting.

Values and beliefs

12. I hold the following values and beliefs that are relevant to my future health care:
I am of the faith and thus request / refuse medical treatment involving blood transfusions or any of the following specified medical products:

Duration of directive

13. This document remains effective until I make it clear, while in sound mind, that my wishes have changed.

Signature and witnessing

14. This declaration is signed and dated by me and confirmed by the two adult witnesses below, in each other's presence.

15. I confirm that the undersigned witnesses are not beneficiaries in my Last Will and Testament and they will not benefit financially from my demise.

Patient's Signature:	Full names:	Date:
Witness 1: Signature: Name: Address: Telephone numbers:		
Witness 2 Signature: Name: Address: Telephone numbers:		

6.2.8 A New Dispensation: Living Wills as Legally Binding Documents

In chapter 1 reference was made to the usefulness of living wills as discussed in the *Cruzan*[1119] case. After a car accident, Cruzan was left in a permanent vegetative state and was fed by a stomach tube. The problem was that Cruzan's parents and the medical personnel disagreed on whether to remove the feeding tube. Seven years after the accident, the Supreme Court of Missouri ruled that the feeding tube could be removed. The issue was that the trial court needed "clear and convincing" evidence what Nancy Cruzan would not have wished to have lived in that state. Witness testimony was later used to prove the required evidence, but it would have been much quicker and simpler, and nature would have been allowed to take its course much earlier, if there had been any documentary proof such as a living will in which she could have expressed her wishes for treatment in times of mental incapacity.

[1119] *Cruzan v Director Missouri Dept of Health* 497 US 261 (1990) in para 1.2.1.

Etheredge makes the important point that in a country such as South Africa with limited medical infrastructure and a struggling economy, it is essential that medical resources should not be wasted. According to Etheredge if Cruzan had a living will, it would have been beneficial to the general public, as Cruzan's medical care would not have cost the State of Missouri so much unnecessary expenditure.[1120] However, the economic issue should be carefully controlled, especially in a country such as South Africa with its struggling economy, limited medical infrastructure and limited medical resources.[1121]

This thesis provides a framework for the legal enforcement of living wills in South Africa to aid law reform in this field. Legal practitioners should ultimately, when the necessary legal recognition is in place, view living wills as legally binding documents. Legal recognition should entail that where a doctor wishes to deviate from the wishes and instructions, clear and convincing arguments such as the "best interests of the patient" will need to be proved. This "best interests of the patient" is currently in place for minors who require blood transfusions. The High Court as upper guardian of all minors in South Africa can order blood transfusions despite objections from the family if it is in the best interest of the minor to do so.[1122] It is a particular object of the End of Life Decisions Bill that a living will document shall absolve medical practitioners from civil and criminal liability, should the treatment or the withholding of such treatment hasten the death of the patient. As discussed in chapter 2, since living wills can ultimately be expanded to include circumstances such as euthanasia and/or assisted suicide, when euthanasia and/or assisted suicide are decriminalised, the legislation on living wills should be comprehensive, well-considered and strict safeguards should apply.[1123]

To enhance the legal validity and effectiveness of living wills, the following principles need to be considered.

[1120] Etheredge H *Enhancing the doctor-patient relationship: living, dying and use of the living will* (2009) (MScMed (Bioethics & Health Law)) 17.
[1121] See discussion on access to health care and the *Soobramoney v Minister of Health, KwaZulu-Natal* 1998 (1) SA 765 (CC) case in Chapter 2 para 2.3.8.
[1122] Cf *Hay v B* 2003 (3) SA 492 (W) discussed in Chapter 2 para 2.3.7.
[1123] See Chapter 2 para 2.4.

6.2.8.1 Accessibility

It is vital that the living will documents be easily accessible, therefore it is recommended at present that they should form part of the patient's medical record. They should for instance be submitted when a patient is submitted to a medical facility such as a hospital. They can also be stored on a national database, once such a database is created.[1124]

6.2.8.2 Amendment and Revocation

When amending a living will, it is advised that the whole document be renewed. When revoking a living will, the whole document should be revoked, destroyed, the word "revoked" written across it, or a letter of revocation must be attached. All copies should be amended or revoked including the copies kept by family friends, attorney, medical practitioners etc. The maker's intention to amend or revoke must be clear.[1125]

6.2.8.3 Presumption of Capacity

The legislation must be all encompassing and needs to contain presumptions such as the presumption of capacity in terms of the Mental Capacity Act in England.[1126]

6.2.8.4 Review of Legislation

Periodic reviews of the legislation must also take place, for example in England the National Mental Capacity Forum was created in an attempt to assess and make recommendations on the interpretation and enforceability issues of the Mental Capacity Act.[1127] In South Africa a similar forum should be created to serve a similar purpose.

[1124] See Chapter 5 para 5.3.4.
[1125] See Chapter 5 para 5.3.5.
[1126] See Chapter 4 para 4.4.3.
[1127] See Chapter 4 para 4.4.3.3.

6.2.8.5 Patient Education

Awareness campaigns should be created to advise patients of living wills, their rights in connection therewith, drafting thereof, the importance of regular updates and the change in circumstances. Such awareness campaigns should be aimed at patients in the public and private sector.

6.2.8.6 Patient Autonomy

Providing a legal framework for living wills (advance directives) will allow doctors to adhere to a patient's instructions and wishes without a fear of prosecution. This will enhance the autonomy of the patient and help to improve the quality of life of patients. It is a particular object of End of Life Decisions Bill that a living will document should absolve medical practitioners from ethical, civil and criminal liability, should the treatment or the withholding of treatment hasten the death of the patient.

6.2.9 The Passage from Life to Death

According to Gwyther:

> "Many people fear the process of dying rather than the fact of dying. This fear is often associated with interventions that may be undertaken at the end of life as well as with the knowledge that suffering may be a part of dying and that both may be associated with loss of dignity of the individual".[1128]

At the end of life, palliative care and medical care to help a patient die without pain or stress are not mutually exclusive, but should work together to assist a patient to the next phase after life. The fundamental values and ethical principles of the health care profession remain that of compassionate care. Perhaps the advances in new medical

[1128] Gwyther L "Withholding and withdrawing treatment: practical applications of ethical principles in end-of-life care" (June 2008) 1 1 *SAJBL* 24.

technology have compelled us to rethink our end-of-life wishes. Perhaps a living will is the best instrument for communicating our deepest end-of-life health care wishes while we are still able to do so.

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