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BYLAAG A:

AANSOEK VIR TOESTEMMING OM NAVORSING BY EENHEID TE DOEN

TOESTEMMINGSBRIEF VAN HOOFSPESIALIS: DR CF SLABBER

Dr. Graham L Cohen, MBChB(UCT), FCP (SA)
Dr. Richard W Eek & MBChB (UP), MMed (Int), FCP (SA)
Dr. Coenraad F Slabber B.Sc. (Med), MBBCh(Wits), FCP (SA)

Specialist Physicians / Medical Oncologists

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Pretoria, South Africa
Fax: (+27-12) 346-6560
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2001-01-12

Ek gee hiermee toestemming dat Johanna Alberta Opperman (studente nommer 9335021) haar MA (MW) met die skripsie titel: “ Die belewenis van ‘n beenmurgoorplantingspasiënt” mag uitvoer in die Mary Potter Onkologie Eenheid.

DR C F SLABBER

Posbus 32797
Glenstantia
0010

2000-12-08

Dr Slabber
Mary Potter Onkologie Eenheid
Pretoria

Geagte dr Slabber,

VOLTOOIING VAN MA-GRAAD TE MARY POTTER ONKOLOGIE EENHEID

Ek wil u persoonlik bedank vir u besondere positiewe bydrae met my MA-studies te Universiteit van Pretoria. Baie dankie vir die toestemming wat u verleen het aan my om my MA –graad by die Mary Potter Onkologie Eenheid kan voltooi. Baie dankie dat u altyd bereid is om mediese aspekte aan my te verduidelik. Graag dra ek ook my dank aan u en u mede-dokters oor vir die studieverlof wat ek pas kon gehad het.

Ek hou u graag op hoogte van die vordering van my studies. Tans is my studies op die stadium waar ek die empiriese ondersoek doen. Dit behels dat elke pasiënt wat 'n stamseloorplanting gehad het die vraelys sal voltooi. Ek het alreeds ongeveer 30 pasiënte geïdentifiseer. Aangeheg vind u 'n voorbeeld van die vraelys. Ek beplan om hierdie ondersoek vanaf middel Desember 2000 – Januarie 2001 te doen.

My studies het reeds gevorder tot op die punt waar ek slegs die empiriese ondersoek moet voltooi en die bevindinge weergee. Ek sal einde Maart 2001 my MA- verhadeling kan afhandel.

Ek onderneem om aan Mary Potter Onkologie Eenheid 'n afskrif van my verhandeling te verskaf.

Vriendelike groete,

HANNETJIE OPPERMAN
(MAATSKAPLIKE WERKER: MARY POTTER ONKOLOGIE EENHEID)

BYLAAG B:

VRAELYS

QUESTIONNAIRE

Dr. Graham L Cohen, MBChB(UCT), FCP (SA)
Dr. Richard W Eek & MBChB (UP), MMed (Int), FCP (SA)
Dr. Coenraad F Slabber B.Sc. (Med), MBBCh(Wits), FCP (SA)

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2001-02-01

Geagte respondent,

Baie dankie dat u deel is van hierdie navorsingsprojek.

Soos telefonies bespreek vind u aangeheg:
- 'n Vraelys
- 'n Koevert om die vraelys terug te pos aan my.

Nogmaals baie dankie,

HANNETJIE OPPERMAN
MAATSKAPLIKE WERKER

Posbus 32797

GLENSTANTIA

0010

Geagte respondent

BEANTWOORDING/INVUL VAN VRAELYS VIR MA(MW) NAGRAADSE STUDIE

Die Mary Potter Onkologie Sentrum glo daarin om ‘n holistiese benadering te volg. Ten einde ‘n omvattende diens aan u en u familie te lewer sal u deelname opreg waardeer word.

Ons wil graag die behoeftes, ervarings en belewenisse van hoë dosering chemoterapie pasiënte ondersoek. Sodoende kan ‘n beter diens gelewer word.

Die vraelys is anoniem en alle inligting sal as hoogs vertroulik beskou word.

Antwoord asseblief die vrae so eerlik as moontlik.

Geen vraag is reg of verkeerd nie.

Baie dankie dat u bereid is om deel te wees van die ondersoek.

Vriendelike groete

HANNETJIE OPPERMAN
MAATSKAPLIKE WERKER

Posbus 32797

GLENSTANTIA

0010

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Vriendelike groete

HANNETJIE OPPERMAN
MAATSKAPLIKE WERKER

VRAELYS: DIE EMOSIONELE BELEWENIS VAN 'N BEENMURGOORPLANTING

VIR KANTOOR GEBRUIK

RESPONDENTNOMMER V1 ☐☐ 1 - 2

INSTRUKSIES:

Merk slegs die toepaslike antwoord of soos anders aangedui:

Voorbeeld

MANLIK	
VROULIK	X

In hierdie vraelys word 'n stamseloorplanting en 'n beenmurgoorplanting as dieselfde prosedure gesien

AFDELING 1 BIOGRAFIESE GEGEWENS

1.1 Geslag

MANLIK	
VROULIK	

V2 ☐ 3

1.2 Hoe oud is u?

______________ jaar

V3 ☐☐ 4 - 5

1.3 Huwelikstaat

Enkel	
Getroud	
Geskei	
Vervreemd	
Wedustaat	
Saamleef Verhouding	
ANDER (spesifiseer)	

V4 ☐ 6

1.4 Hoeveel kinders het u?

Aantal	
Geen	
1	
2	
3	
4	
5 of meer	

V5 ☐☐ 7 - 8

V 6 ☐☐ 9 - 10

VRAELYS: DIE EMOSIONELE BELEWENIS VAN 'N BEENMURGOORPLANTING

VIR KANTOOR GEBRUIK

RESPONDENTNOMMER V1 ☐☐ 1 - 2

INSTRUKSIES:

Merk slegs die toepaslike antwoord of soos anders aangedui:

Voorbeeld

MANLIK	
VROULIK	X

In hierdie vraelys word 'n stamseloorplanting en 'n beenmurgoorplanting as dieselfde prosedure gesien

AFDELING 1 BIOGRAFIESE GEGEWENS

1.1 Geslag

MANLIK	
VROULIK	

V2 ☐ 3

1.2 Hoe oud is u?

_______________ jaar

V3 ☐☐ 4 - 5

1.3 Huwelikstaat

Enkel	
Getroud	
Geskei	
Vervreemd	
Wedustaat	
Saamleef Verhouding	
ANDER (spesifiseer)	

V4 ☐ 6

1.4 Hoeveel kinders het u?

Aantal	
Geen	
1	
2	
3	
4	
5 of meer	

V5 ☐☐ 7 - 8

V 6 ☐☐ 9 - 10

1.5 Waar is u woonagtig?

In Pretoria	
Buite Pretoria	

V7 ☐ 11

1.6 Wat is u opvoedkundige kwalifikasie?

Geen opleiding	
Standard 8 of laer	
Matriek	
Diploma	
Graad	

V8 ☐ 12

1.5 Waar is u woonagtig?

In Pretoria	
Buite Pretoria	

V7 ☐ 11

1.6 Wat is u opvoedkundige kwalifikasie?

Geen opleiding	
Standard 8 of laer	
Matriek	
Diploma	
Graad	

V8 ☐ 12

AFDELING 2 MEDIESE GEGEWENS

2.1.1 Watter tipe onkologiese of hematologiese siektetoestand het u?

V9 ☐☐ 13-14

2.1.2 In watter jaar is u gediagnoseer met u siektetoestand?

V10 ☐☐☐☐ 15-18

2.2.1 Het u chemoterapie behandeling voor die stamseloorplanting gehad?

Ja	
Nee	

V11 ☐ 19

2.2.2 Indien u ja geantwoord het op vraag 2.2.1, Beantwoord die volgende vraag

Waar het u die behandeling ontvang?

Spreekkamer	
Mary Potter saal	
Ander	

V12 ☐ 20

2.3.1 Dink u dit is belangrik om voorbereiding te ontvang voor 'n stamseloorplanting?

Ja	
Nee	

V13 ☐ 21

Motiveer, u antwoord

____

____

V14 ☐☐ 22-23
V15 ☐☐ 24-25
V16 ☐☐ 26-27
V17 ☐☐ 28-29
V18 ☐☐ 30-31

AFDELING 2 MEDIESE GEGEWENS

2.1.1 Watter tipe onkologiese of hematologiese siektetoestand het u?

V9 ☐☐ 13-14

2.1.2 In watter jaar is u gediagnoseer met u siektetoestand?

V10 ☐☐☐☐ 15-18

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V11 ☐ 19

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Mary Potter saal	
Ander	

V12 ☐ 20

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Ja	
Nee	

V13 ☐ 21

Motiveer, u antwoord

____

____

V14 ☐☐ 22-23
V15 ☐☐ 24-25
V16 ☐☐ 26-27
V17 ☐☐ 28-29
V18 ☐☐ 30-31

2.4 Was die voorbereiding wat u en u familie saam met die beenmurgoorplantingspan ontvang het voldoende?

Ja	
Nee	

V19 ☐ 32

Motiveer u antwoord

______________________________ V20 ☐☐ 33

______________________________ V21 ☐☐ 34

______________________________ V22 ☐☐ 35

2.5 Watter tipe inligting dink u is van uiterste belang vir 'n voornemende beenmurgoorplantingpasiënt om te hê?

(Merk alles van toepassing)

Algemene verloop van die behandeling		V23	☐	36
Emosionele impak van die behandeling		V24	☐	37
Riglyne vir die hantering van die tydperk		V25	☐	38
Algemene inligting oor die saal byvoorbeeld besoektye, ens		V26	☐	39
Om met 'n beenmurgoorplantings pasiënt te praat wat alreeds deur die prosedure is.		V27	☐	40
Meer spesifieke inligting oor:				
a) Oesing van die stamselle, indien van toepassing		V28	☐	41
b) Toediening van die hoë dosisse chemoterapie		V29	☐	42
c) Newe-effekte van die chemoterapie		V30	☐	43
d) Isolasie tydperk		V31	☐	44
e) Emosionele impak van die prosedure		V32	☐	45 - 46
Funksionering van die multi-professionele span		V33	☐	47 - 48
Ander		V34	☐	49

2.4 Was die voorbereiding wat u en u familie saam met die beenmurgoorplantingspan ontvang het voldoende?

Ja	
Nee	

V19 ☐ 32

Motiveer u antwoord

____ V20 ☐☐ 33
____ V21 ☐☐ 34
____ V22 ☐☐ 35

2.5 Watter tipe inligting dink u is van uiterste belang vir 'n voornemende beenmurgoorplantingpasiënt om te hê?

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e) Emosionele impak van die prosedure		V32	☐	45 - 46
Funksionering van die multi-professionele span		V33	☐	47 - 48
Ander		V34	☐	49

2.6 Hoe het u die hoë dosis chemoterapie behandeling ervaar?

(Merk 1 (een) wat van toepassing is)

Pynvol				
Ongemaklik		V35	☐	50
Hanteerbaar				
Geen ongemak				

2.7 Watter van die volgende simptome het u ervaar tydens u hospitalisasie? (Merk alles van toepassing)

Geen		V36	☐	51
Hoofpyn		V37	☐	52
Slaaploosheid		V38	☐	53
Spierspasma's		V39	☐	54
Moegheid		V40	☐	55
Naarheid		V41	☐	56
Swakheid		V42	☐	57
Ander (spesifiseer)		V43	☐	58-59

____

____ V44 ☐ 60-61

2.6 Hoe het u die hoë dosis chemoterapie behandeling ervaar?

(Merk 1 (een) wat van toepassing is)

Pynvol				
Ongemaklik		V35	☐	50
Hanteerbaar				
Geen ongemak				

2.7 Watter van die volgende simptome het u ervaar tydens u hospitalisasie? (Merk alles van toepassing)

Geen		V36	☐	51
Hoofpyn		V37	☐	52
Slaaploosheid		V38	☐	53
Spierspasma's		V39	☐	54
Moegheid		V40	☐	55
Naarheid		V41	☐	56
Swakheid		V42	☐	57
Ander (spesifiseer)		V43	☐	58-59

____

____ V44 ☐ 60-61

AFDELING 3 PSIGO-SOSIALE DATA

3.1 Watter gevoelens het u ervaar voor en na die stamseloorplanting

(Merk alles van toepassing)

GEVOELENS	VOOR die stamsel-oorplanting	NA die stamseloor-planting			
Gevoelens van skok			V45	☐	62-63
Gevoelens van angs			V47	☐	64-65
Gevoelens van geluk			V49	☐	66-67
Gevoelens van geïrriteerdheid			V51	☐	68-69
Gevoelens van depressie			V53	☐	70-71
Gevoelens van skuld			V55	☐	72-73
Gevoelens van woede			V57	☐	74-75
Gevoelens van onsekerheid			V59	☐	76-77
Gevoelens van onveiligheid			V61	☐	78-79
Gevoelens dat ek gestraf word			V63	☐	80-81
Neutraal			V65	☐	82-83

3.2 Wat is u belangrikste belewenis ten opsigte van u siekte?

	VOOR die stamsel-oorplanting	NA die stamseloor-planting			
Aanvaarding van my siekte					
Dankbaar dat ek lewe			V66	☐	84
Ek is gesond					
Ek is teleurgesteld			V67	☐	85
Wil nie oor situasie praat nie					
Wil graag alleen gelaat word					
Onsekerheid oor die toekoms					

AFDELING 3 PSIGO-SOSIALE DATA

3.1 Watter gevoelens het u ervaar voor en na die stamseloorplanting

(Merk alles van toepassing)

GEVOELENS	VOOR die stamsel-oorplanting	NA die stamseloor-planting			
Gevoelens van skok			V45		62-63
Gevoelens van angs			V47		64-65
Gevoelens van geluk			V49		66-67
Gevoelens van geïrriteerdheid			V51		68-69
Gevoelens van depressie			V53		70-71
Gevoelens van skuld			V55		72-73
Gevoelens van woede			V57		74-75
Gevoelens van onsekerheid			V59		76-77
Gevoelens van onveiligheid			V61		78-79
Gevoelens dat ek gestraf word			V63		80-81
Neutraal			V65		82-83

3.2 Wat is u belangrikste belewenis ten opsigte van u siekte?

	VOOR die stamsel-oorplanting	NA die stamseloor-planting			
Aanvaarding van my siekte					
Dankbaar dat ek lewe			V66		84
Ek is gesond					
Ek is teleurgesteld			V67		85
Wil nie oor situasie praat nie					
Wil graag alleen gelaat word					
Onsekerheid oor die toekoms					

3.3 Het u enige van die onderstaande emosies ondervind voor en na u behandeling?

	VOOR die stamsel-oorplanting	NA die stamseloor-planting			
Ek was bang vir die dood			V69	☐	86-87
Ek was bang vir die toekoms			V71	☐	88-89
Ek was bang vir die newe-effekte van die behandeling			V73	☐	90-91
Ek was bekommerd oor my familie			V75	☐	92-93
Bang dat ek alleen sal voel			V77	☐	94-95

3.4 Hoe dikwels dink u tans aan u siekte?

Heeldag/Altyd				
Dikwels		V78	☐	96
Selde				
Nooit				

3.5 Watter persone het aan u ondersteuning gebied tydens u hospitalisasie?

(Merk al die persone wat 'n rol gespeel het

Eggenoot		V79	☐	97
Vriend/vriendin		V80	☐	98
Gesin		V81	☐	99
Familie		V82	☐	100
Vriende		V83	☐	101
Kerk-vriende		V84	☐	102
Ander (spesifiseer)		V85	☐	103

______________________________ V86 ☐ 104

______________________________ V87 ☐ 105

3.3 Het u enige van die onderstaande emosies ondervind voor en na u behandeling?

	VOOR die stamsel-oorplanting	NA die stamseloor-planting			
Ek was bang vir die dood			V69	☐	86-87
Ek was bang vir die toekoms			V71	☐	88-89
Ek was bang vir die newe-effekte van die behandeling			V73	☐	90-91
Ek was bekommerd oor my familie			V75	☐	92-93
Bang dat ek alleen sal voel			V77	☐	94-95

3.4 Hoe dikwels dink u tans aan u siekte?

Heeldag/Altyd				
Dikwels		V78	☐	96
Selde				
Nooit				

3.5 Watter persone het aan u ondersteuning gebied tydens u hospitalisasie?

(Merk al die persone wat 'n rol gespeel het

Eggenoot		V79	☐	97
Vriend/vriendin		V80	☐	98
Gesin		V81	☐	99
Familie		V82	☐	100
Vriende		V83	☐	101
Kerk-vriende		V84	☐	102
Ander (spesifiseer)		V85	☐	103

____________________ V86 ☐ 104

____________________ V87 ☐ 105

3.6 Watter professionele persone het aan u ondersteuning gebied tydens u hospitalisasie?

(Merk alle persone wat 'n rol speel)

Mediese dokters		V88		106-107
Verpleegpersoneel		V89		108-109
Maatskaplike werker		V90		110-111
Predikant/geestelike leier		V91		112-113
Ander (Spesifiseer)		V92		114-115

________________________________ V93 ☐ 116

3.7 Wanneer dink u moet die maatskaplike werker u vir berading sien?

(Merk almal wat van toepassing is)

Voor die stamseloorplanting		V94		117
Tydens u hospitalisasie		V95		118
Na u ontslag		V96		119

3.8 Het u enige veranderinge in u huweliksverhouding/vriendskap met u eggenoot/betekkenesvolle ander ervaar na u opname in die saal?

(Merk almal wat van toepassing is)

My verhouding het verbeter		V97		120
My verhouding is hegter		V98		121
My verhouding het verswak		V99		122
My rol het verander		V100		123
Ek ervaar 'n gebrek aan ondersteuning		V101		124
Ek ervaar konflik		V102		125
Ek ervaar dat my maat my vermy		V103		126

3.6 Watter professionele persone het aan u ondersteuning gebied tydens u hospitalisasie?

(Merk alle persone wat 'n rol speel)

Mediese dokters		V88		106-107
Verpleegpersoneel		V89		108-109
Maatskaplike werker		V90		110-111
Predikant/geestelike leier		V91		112-113
Ander (Spesifiseer)		V92		114-115

______________________________ V93 ☐ 116

3.7 Wanneer dink u moet die maatskaplike werker u vir berading sien?

(Merk almal wat van toepassing is)

Voor die stamseloorplanting		V94		117
Tydens u hospitalisasie		V95		118
Na u ontslag		V96		119

3.8 Het u enige veranderinge in u huweliksverhouding/vriendskap met u eggenoot/betekkenesvolle ander ervaar na u opname in die saal?

(Merk almal wat van toepassing is)

My verhouding het verbeter		V97		120
My verhouding is hegter		V98		121
My verhouding het verswak		V99		122
My rol het verander		V100		123
Ek ervaar 'n gebrek aan ondersteuning		V101		124
Ek ervaar konflik		V102		125
Ek ervaar dat my maat my vermy		V103		126

3.9 Het u enige veranderinge in u verhouding met u familie ervaar na u opname in die saal?

(Merk almal wat van toepassing is)

My verhouding het verbeter		V104			127
My verhouding is hegter		V105			128
My verhouding het verswak		V106			129
My rol het verander		V107			130
Ek ervaar 'n gebrek aan ondersteuning		V108			131
Ek ervaar konflik		V109			132
Ek ervaar dat my familiet my vermy		V110			133

3.10 Watter aspekte het u sosiale interaksie (byvoorbeeld kuier) beïnvloed?

(Merk almal wat van toepassing is)

Fisiese simptome (naarheid, mondsere, moegheid)		V111		134
Fisiese voorkoms (uitslag op vel, verlies aan hare)		V112		135
Hospitalisasie		V113		136
Isolasie tydperk (Vriende word aangeraai om later u tuis of uit isolasie te besoek)		V114		137
Familie en vriende bly ver		V115		140

3.11 Watter veranderinge was daar in die familie opset tuis tydens u hospitalisasie?

(Merk net die belangrikste verandering)

Meer pligte op u eggenoot	Ja	Nee
Meer pligte op familie lede en vriende om te help met praktiese reëlings	Ja	Nee
Daar was meer onderlinge spanning in die huishouding	Ja	Nee
Rolveranderinge het ingetree	Ja	Nee
Ander	Ja	Nee

____

____

V116		141-142
V117		143-144
V118		145-146
V119		147-148
V120		149-150
V121		151-152
V122		153-154

3.9 Het u enige veranderinge in u verhouding met u familie ervaar na u opname in die saal?

(Merk almal wat van toepassing is)

My verhouding het verbeter		V104			127
My verhouding is hegter		V105			128
My verhouding het verswak		V106			129
My rol het verander		V107			130
Ek ervaar 'n gebrek aan ondersteuning		V108			131
Ek ervaar konflik		V109			132
Ek ervaar dat my familiet my vermy		V110			133

3.10 Watter aspekte het u sosiale interaksie (byvoorbeeld kuier) beïnvloed?

(Merk almal wat van toepassing is)

Fisiese simptome (naarheid, mondsere, moegheid)		V111		134
Fisiese voorkoms (uitslag op vel, verlies aan hare)		V112		135
Hospitalisasie		V113		136
Isolasie tydperk (Vriende word aangeraai om later u tuis of uit isolasie te besoek)		V114		137
Familie en vriende bly ver		V115		140

3.11 Watter veranderinge was daar in die familie opset tuis tydens u hospitalisasie?

(Merk net die belangrikste verandering)

Meer pligte op u eggenoot	Ja	Nee	V116		141-142
Meer pligte op familie lede en vriende om te help met praktiese reëlings	Ja	Nee	V117		143-144
Daar was meer onderlinge spanning in die huishouding	Ja	Nee	V118		145-146
Rolveranderinge het ingetree	Ja	Nee	V119		147-148
Ander	Ja	Nee	V120		149-150

____

____

V121		151-152
V122		153-154

3.12 Nadat u ontslaan is uit die hospitaal, het u plek by die huis verander?

(Merk almal van toepassing)

Ek het hulp nodig gehad met praktiese aspekte (soos bad), omdat ek nog baie swak was.		V123	☐	155
Familielede het verantwoordelikhede van my afgehaal sodat ek kon herstel		V124	☐	156
Bekommernisse en probleme is van my weggehou, om my nie onnodig te ontstel nie.		V125	☐	157
Familielede was oorbeskermd oor my gesondheid en welstand.		V126	☐	158
My verswakte toestand het my en my familie gefrustreer		V127	☐	159

3.13 Het u spanning ervaar voor en/of tydens u hospitalisasie?

	Voor die opname	Na u opname			
Baie spanning			V128	☐	160
Matige spanning					
Min spanning			V129	☐	161
Geen spanning					

Motiveer

______________________________ V130 ☐ 162

______________________________ V131 ☐ 163

______________________________ V132 ☐ 164

3.14 Watter tipe stres simptome het u ervaar?

(Merk almal van toepassing)

Tipe stres simptome	Voor die opname	Tydens hospitalisasie			
Hartkloppings			V133	☐☐	165-166
Sweterige handpalms			V134	☐☐	167-168
Kortasemigheid			V135	☐☐	169-170
Hoofpyn			V136	☐☐	171-172
Beweriglheid, in bene, arms en/of hande			V137	☐☐	173-174
Skoenlappers op my maag			V138	☐☐	175-176
Gebalde vuise of geklemde kake			V139	☐☐	177-178
Nagmerries			V140	☐☐	179-180
Ander			V141	☐☐	181-182

______________________________ V142 ☐☐ 183-184

3.12 Nadat u ontslaan is uit die hospitaal, het u plek by die huis verander?

(Merk almal van toepassing)

Ek het hulp nodig gehad met praktiese aspekte (soos bad), omdat ek nog baie swak was.		V123 ☐	155
Familielede het verantwoordelikhede van my afgehaal sodat ek kon herstel		V124 ☐	156
Bekommernisse en probleme is van my weggehou, om my nie onnodig te ontstel nie.		V125 ☐	157
Familielede was oorbeskermd oor my gesondheid en welstand.		V126 ☐	158
My verswakte toestand het my en my familie gefrustreer		V127 ☐	159

3.13 Het u spanning ervaar voor en/of tydens u hospitalisasie?

	Voor die opname	Na u opname		
Baie spanning			V128 ☐	160
Matige spanning				
Min spanning			V129 ☐	161
Geen spanning				

Motiveer

______________________________ V130 ☐ 162

______________________________ V131 ☐ 163

______________________________ V132 ☐ 164

3.14 Watter tipe stres simptome het u ervaar?

(Merk almal van toepassing)

Tipe stres simptome	Voor die opname	Tydens hospitalisasie		
Hartkloppings			V133 ☐☐	165-166
Sweterige handpalms			V134 ☐☐	167-168
Kortasemigheid			V135 ☐☐	169-170
Hoofpyn			V136 ☐☐	171-172
Bewerigheid, in bene, arms en/of hande			V137 ☐☐	173-174
Skoenlappers op my maag			V138 ☐☐	175-176
Gebalde vuise of geklemde kake			V139 ☐☐	177-178
Nagmerries			V140 ☐☐	179-180
Ander			V141 ☐☐	181-182

______________________________ V142 ☐☐ 183-184

3.15.1 In watter mate is u selfbeeld beïnvloed deur u behandeling?

Baie	
Matig	
Min	
Geen	

V143 ☐ 185

3.15.2 Noem 'n voorbeeld van hoe u selfbeeld beïnvloed is?

________________________________ V144 ☐ 186
________________________________ V145 ☐ 187
________________________________ V146 ☐ 188
________________________________ V147 ☐ 189

3.16.1 In watter mate is u seksuele lewe met u metgesel beïnvloed deur u hospitalisasie?

Baie	
Matig	
Min	
Nie van toepassing	

V148 ☐ 190

3.16.2 Indien daar 'n invloed was, wat sou u sê het die grootste invloed gehad?

Fisiese simptome (soos moegheid, naarheid, mondsere)	
Fisiese voorkoms (haarverlies, uitslag op vel)	
Gebrek aan privaatheid in die hospitaal	
Nie van toepassing	

V149 ☐ 191

3.15.1 In watter mate is u selfbeeld beïnvloed deur u behandeling?

Baie	
Matig	
Min	
Geen	

V143 ☐ 185

3.15.2 Noem 'n voorbeeld van hoe u selfbeeld beïnvloed is?

____ V144 ☐ 186

____ V145 ☐ 187

____ V146 ☐ 188

____ V147 ☐ 189

3.16.1 In watter mate is u seksuele lewe met u metgesel beïnvloed deur u hospitalisasie?

Baie	
Matig	
Min	
Nie van toepassing	

V148 ☐ 190

3.16.2 Indien daar 'n invloed was, wat sou u sê het die grootste invloed gehad?

Fisiese simptome (soos moegheid, naarheid, mondsere)	
Fisiese voorkoms (haarverlies, uitslag op vel)	
Gebrek aan privaatheid in die hospitaal	
Nie van toepassing	

V149 ☐ 191

3.17 Hoe was u werk beïnvloed deur u hospitalisasie?

	Ja	Nee	NVT			
My werkgewer het aan my siekteverlof toegestaan				V150	☐☐	192
Ek moes onbetaalde verlof geneem het				V151	☐☐	193
My bevorderings moontlikhede is in gedrang as gevolg van my lang hospitalisasie				V152	☐☐	194
My werkgewer het my tegemoed gekom sover dit moontlik was				V153	☐☐	195
Ek moes op vervroegde pensioen gaan				V154	☐☐	196
Ek is medies ongeskik verklaar				V155	☐☐	197
My werkgewer/kollegas het my ondersteun deur my gereeld te besoek				V156	☐☐	198
Ek het geen probleme ervaar nie				V157	☐☐	199
Ander (spesifiseer)				V158	☐☐	200

______________________ V159 ☐☐ 201

______________________ V160 ☐☐ 202

3.18 Sou u graag wou hê dat 'n personeellid van die praktyk met u werkgewer moes skakel om u verblyf in die hospitaal te bespreek?

Ja		V161	☐	203
Nee				

Motiveer bogenoemde antwoord

______________________ V162 ☐☐ 204

______________________ V163 ☐☐ 205

______________________ V164 ☐☐ 206

______________________ V165 ☐☐ 207

3.17 Hoe was u werk beïnvloed deur u hospitalisasie?

	Ja	Nee	NVT				
My werkgewer het aan my siekteverlof toegestaan				V150			192
Ek moes onbetaalde verlof geneem het				V151			193
My bevorderings moontlikhede is in gedrang as gevolg van my lang hospitalisasie				V152			194
My werkgewer het my tegemoed gekom sover dit moontlik was				V153			195
Ek moes op vervroegde pensioen gaan				V154			196
Ek is medies ongeskik verklaar				V155			197
My werkgewer/kollegas het my ondersteun deur my gereeld te besoek				V156			198
Ek het geen probleme ervaar nie				V157			199
Ander (spesifiseer)				V158			200

______________________________ V159 ☐☐ 201

______________________________ V160 ☐☐ 202

3.18 Sou u graag wou hê dat 'n personeellid van die praktyk met u werkgewer moes skakel om u verblyf in die hospitaal te bespreek?

Ja		V161	☐	203
Nee				

Motiveer bogenoemde antwoord

______________________________ V162 ☐☐ 204

______________________________ V163 ☐☐ 205

______________________________ V164 ☐☐ 206

______________________________ V165 ☐☐ 207

3.19.1 Sou u graag wou hê dat daar meer inligting aan u werkgewer verskaf word insake u stamsel-oorplanting?

Ja		V166	☐	208
Nee				

3.19.2 Indien u ja geantwoord het op vraag 3.20.1, beantwoord die volgende vraag.

(Merk almal wat van toepassing is)

Op watter wyse sal u voorstel moet daar inligting aan u werkgewer verskaf word.

	Ja	Nee			
'n Persoonlike besoek aan u werkgewer vanaf 'n personeellid van die praktyk			V167	☐☐	209
Deur middel van 'n brosjure algemene inligting te verskaf oor u behandeling			V168	☐☐	210
'n Oproep na u werkgewer om algemene inligting te verskaf.			V169	☐☐	211

3.20 Is u algemene finansiële posisie beïnvloed deur u hospitalisasie?

Ja		V170	☐	212
Nee				

3.21 In watter mate is u mediese fonds beïnvloed deur u stamseloorplanting?

My mediese fonds het alle koste gedra.	Ja	Nee	V171	☐☐	213
My mediese fonds is uitgeput na die stamseloorplanting	Ja	Nee	V172	☐☐	214
Ek moes bybetalings betaal het	Ja	Nee	V173	☐☐	215
Ek is 'n privaat pasiënt en dra my eie koste self	Ja	Nee	V174	☐☐	216

3.19.1 Sou u graag wou hê dat daar meer inligting aan u werkgewer verskaf word insake u stamsel-oorplanting?

Ja		V166	☐	208
Nee				

3.19.2 Indien u ja geantwoord het op vraag 3.20.1, beantwoord die volgende vraag.

(Merk almal wat van toepassing is)

Op watter wyse sal u voorstel moet daar inligting aan u werkgewer verskaf word.

	Ja	Nee			
'n Persoonlike besoek aan u werkgewer vanaf 'n personeellid van die praktyk			V167	☐☐	209
Deur middel van 'n brosjure algemene inligting te verskaf oor u behandeling			V168	☐☐	210
'n Oproep na u werkgewer om algemene inligting te verskaf.			V169	☐☐	211

3.20 Is u algemene finansiële posisie beïnvloed deur u hospitalisasie?

Ja		V170	☐	212
Nee				

3.21 In watter mate is u mediese fonds beïnvloed deur u stamseloorplanting?

My mediese fonds het alle koste gedra.	Ja	Nee	V171	☐☐	213
My mediese fonds is uitgeput na die stamseloorplanting	Ja	Nee	V172	☐☐	214
Ek moes bybetalings betaal het	Ja	Nee	V173	☐☐	215
Ek is 'n privaat pasiënt en dra my eie koste self	Ja	Nee	V174	☐☐	216

3.22 Hoe sien u die toekoms vir uself?

____ V175 ☐ 217
____ V176 ☐ 218
____ V177 ☐ 219
____ V178 ☐ 220

____

3.23 Is daar enigiets anders wat u sou aanbeveel waarop ons kan let?

____ V179 ☐☐ 221
____ V180 ☐☐ 222
____ V181 ☐☐ 223
____ V182 ☐☐ 224

DANKIE VIR U SAMEWERKING !!!

3.22 Hoe sien u die toekoms vir uself?

______________________________	V175		217
______________________________	V176		218
______________________________	V177		219
______________________________	V178		220

____

3.23 Is daar enigiets anders wat u sou aanbeveel waarop ons kan let?

______________________________	V179			221
______________________________	V180			222
______________________________	V181			223
______________________________	V182			224

DANKIE VIR U SAMEWERKING !!!

QUESTIONNAIRE: THE EMOTIONAL EXPERIENCE OF A BONE-MARROW TRANSPLA

FOR OFFICE USE

RESPONDENT NUMBER V1 ☐☐ 1 - 2

INSTRUCTIONS:

Mark only the relevant answer or as indicated:

Example

MALE	
FEMALE	X

In this questionnaire a stem cell transplant and a bone-marrow transplant are considered as the same procedure.

SECTION 1 BIOGRAPHICAL DETAILS

1.1 Gender

MALE	
FEMALE	

V2 ☐ 3

.2 Current age

__________ years

V3 ☐☐ 4 - 5

1.3 Marital state

Single	
Married	
Divorced	
Estranged	
Widow/Widower	
Co-habit	
OTHER (specify)	

V4 ☐ 6

4 How many children do you have?

Number	
None	
1	
2	
3	
4	
5 or more	

V5 ☐☐ 7 - 8

V6 ☐☐ 9 - 10

.5 Where do you live?

In Pretoria	
Outside Pretoria	

V7 ☐ 11

.6 What are your educational qualifications?

No training	
Standard 8 (Grade 10) or lower	
Matric (Grade 12)	
Diploma	
Degree	

V8 ☐ 12

SECTION 2 MEDICAL DETAILS

2.1.1 What type of oncological or haematological state of sickness do you have?

V9 ☐☐ 13 - 14

2.1.2 In which yeare were you diagnosed with your illness? V10 ☐☐☐☐ 15 - 18

.2.1 Did you receive chemotherapy before the stem cell transplant?

Yes	
No	

V11 ☐ 19

2.2.2 If you have answered yes to question 2.2.1 answer the following question.

Where did you receive treatment?

Consulting rooms	
Mary Potter ward	
Other	

V12 ☐ 20

3.1 Do you think it is important to be prepared before undergoing a stem cell transplant?

Yes	
No	

V13 ☐ 21

Motivate your answer

____

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V14 ☐☐ 22 - 23
V15 ☐☐ 24 - 25
V16 ☐☐ 26 - 27
V17 ☐☐ 28 - 29
V18 ☐☐ 30 - 31

.4 Was the preparation that you and your family received with the team of the bone-marrow transplant sufficient?

Yes		V19	☐	32
No				

Motivate your answer

____ V20 ☐☐ 33

____ V21 ☐☐ 34

____ V22 ☐☐ 35

2.5 What kind of information do you think is of the utmost importance for a prospective bone-marrow transplant patient?

(Mark everything applicable)

General progress of treatment			V23	☐	36
Emotional impact of the treatment			V24	☐	37
Guidelines for the management of the period			V25	☐	38
General information regarding the ward, for example visiting hours, etc.			V26	☐	39
To speak to a bone-marrow transplant patient who has already undergone the procedure			V27	☐	40
More specific information regarding:					
a)	Harvesting of the stem cells, if applicable		V28	☐	41
b)	Administering of high dosages chemotherapy		V29	☐	42
c)	Side-effects of the chemotherapy		V30	☐	43
d)	Period of isolation		V31	☐	44
e)	Emotional impact of the procedure		V32	☐	45
Functioning of the multi-professional team			V33	☐	46
Other			V34	☐	47

.6 How did you experience the high dosage chemotherapy?

Painful				
Uncomfortable		V35	☐	50
Manageable				
No discomfort				

7 Which of the following symptoms did you experience during your hospitalisation? (Mark everything applicable)

None		V36	☐	51
Headache		V37	☐	52
Insomnia		V38	☐	53
Muscle spasms		V39	☐	54
Tiredness		V40	☐	55
Nausea		V41	☐	56
Weakness		V42	☐	57
Other (specify)		V43	☐	58-59

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____ V44 ☐ 60-61

SECTION 3 PSYCHO-SOCIAL DATA

.1 What feelings did you experience before and after the stem cell transplant?

(Mark everything applicable)

FEELINGS	BEFORE stem cell transplant	AFTER stem cell transplant			
Feelings of shock			V45		62-63
Feelings of anxiety			V47		64-65
Feelings of happiness			V49		66-67
Feelings of irritability			V51		68-69
Feelings of depression			V53		70-71
Feelings of guilt			V55		72-73
Feelings of anger			V57		74-75
Feelings of uncertainty			V59		76-77
Feelings of insecurity			V61		78-79
Feelings that you are punished			V63		80-81
Neutral			V65		82-83

3.2 What is your most important experience regarding your illness?

	BEFORE stem cell transplant	AFTER stem cell transplant			
Acceptance of my illness					
Thankful that I am alive			V66		84
I am healthy					
I an disappointed			V67		85
I do not want to talk about the situation					
I preferably want to be left alone					
Unsure about the future					

3.3 Did you experience any of the under-mentioned emotions before and after your treatment?

	BEFORE stem cell transplant	AFTER stem cell transplant			
I was afraid of death			V69	☐	86-87
I was afraid of the future			V71	☐	88-89
I was afraid of the side-effects of the treatment			V73	☐	90-91
I was worried about my family			V75	☐	92-93
I was afraid that I will feel alone			V77	☐	94-95

3.4 How often do you think about your illness?

The whole day / Always				
Frequently		V78	☐	96
Seldom				
Never				

5 Who supported you during your hospitalisation?

(Mark all the role players)

Spouse		V79	☐	97
Friend		V80	☐	98
???		V81	☐	99
Family		V82	☐	100
Friends		V83	☐	101
Chruch friends		V84	☐	102
Other (specify)		V85	☐	103

______________________________ V86 ☐ 104

______________________________ V87 ☐ 105

3.6 What professional persons supported you during your hospitalisation?

(Mark all the role players)

Medical practitioners		V88		106-107
Nursing staff		V89		108-109
Social worker		V90		110-111
Minister/Spiritual leader		V91		112-113
Other (specify)		V92		114-115

____ V93 116

.7 When do you think should the social worker see you for counselling?

(Mark everything applicable)

Before the stem cell transplant		V94		117
During your hospitalisation		V95		118
After your discharge		V96		119

3.8 After your admission to the ward, did you experience any changes in your marital relationship / friendship with your spouse / meaningful other?

(Mark every item that is applicable)

My relationship improved		V97		120
My relationship is stronger		V98		121
My relationship has deteriorated		V99		122
My role has changed		V100		123
I experience a lack of support		V101		124
I experience conflict		V102		125
I experience that my partner avoids me		V103		126

3.9 After your admission to the ward, did you experience any changes in your relaltionship with your family?

(Mark every item that is applicable)

My relationship improved		V104			127
My relationship is stronger		V105			128
My relationship has deteriorated		V106			129
My role has changed		V107			130
I experience a lack of support		V108			131
I experience conflict		V109			132
I experience that my family avoids me		V110			133

3.10 What aspects influenced your social interaction (e.g. visiting)?

(Mark every item that is applicable)

Physical symtoms (nausea, mouth sores, tiredness)		V111		134
Physical appearance (rash, loss of hair)		V112		135
Hospitalisation		V113		136
Period of isolation (friends are advised to visit you later at home or after you are out of isolation)		V114		137
Family and friends live far away		V115		140

11 What changes were there in the family set-up at home during your hospitalisation?

(Mark every item that is applicable)

More responsibilities on your spouse	Yes	No	V116		141-142
More responsibilities on family and friends to help with pratical arrangements	Yes	No	V117		143-144
There was more internal tension in the household	Yes	No	V118		145-146
There were some changes in roles	Yes	No	V119		147-148
Other	Yes	No	V120		149-150

______________________________ V121 ☐ 151-152

______________________________ V122 ☐ 153-154

.12 Did your role at home change after your discharge?

(Mark every item that is applicable)

I needed help with practical aspects (e.g. bathing), because I was still very weak		V123		155
Family members relieved met from my responsibilities so that I could recuperate		V124		156
Worries and problems were kept away to avoid my being unnecessarily upset		V125		157
Family members were over-protective of my health and well-being		V126		158
My weakened condition frustrated my family and me		V127		159

3.13 Did you experience tension before and/or during your hospitalisation?

	Before admission	After admission
Extreme tension		
Moderate tension		
Little tension		
No tension		

V128 ☐ 160

V129 ☐ 161

Motivate ____________________

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V130 ☐ 162

V131 ☐ 163

V132 ☐ 164

3.14 What types of stress symptoms did you experience?

(Mark every item that is applicable)

	Before admission	After admission				
Palpitations			V133			165-166
Sweaty palms			V134			167-168
Shortness of breath			V135			169-170
Headache			V136			171-172
Trembling in legs, arms and/or hands)			V137			173-174
Butterflies in my stomach			V138			175-176
Clenched fists or clenched jaws			V139			177-178
Nightmares			V140			179-180
Other			V141			181-182

____________________ V142 ☐☐ 183-184

3.15.1 To what extent was your self-image influenced by your treatment?

Much	
Moderate	
Little	
None	

V143 ☐ 185

3.15.2 Give an example of how your self-image was influenced.

______________________________ V144 ☐ 186

______________________________ V145 ☐ 187

______________________________ V146 ☐ 188

______________________________ V147 ☐ 189

3.16.1 To what extent was your sexual life with your partner influenced by your hospitalisation?

Much	
Moderate	
Little	
Not applicable	

V148 ☐ 190

3.16.2 If there was any influence, what would you say had the most influence?

Physical symptoms (e.g. tiredness, nauseous, mouth sores)	
Physical appearance (loss of hair, rash)	
Lack of privacy in the hospital	
Not applicable	

V149 ☐ 191

3.17 In what way was your work influenced by your hospitalisation?

	Yes	No	N/A
My employer granted me sick leave			
I had to take unpaid leave			
The possibilities for promotion was in question as a result of the long period of my hospitalisation			
My employer accommodated me as fas as possible			
I had to go on early retirement			
I was declared medically unfit			
My employer/colleagues supported met by visiting me regularly			
I experienced no problems			
Other (specify)			

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V150			192
V151			193
V152			194
V153			195
V154			196
V155			197
V156			198
V157			199
V158			200
V159			201
V160			202

.18 Would you have preferred that a staff member of the practice communicate with your employer to discuss your stay in the hospital?

Yes	
No	

V161		203

Motivate your answer

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V162			204
V163			205
V164			206
V165			207

3.19.1 Would you prefer that your employer is supplied with more information regarding stem cell transplant?

Yes	
No	

V166		208

3.19.2 If you have answered yes to question 3.19.1, answer the following question:
(Mark every item that is applicable)

In which way do you think information should be supplied to your employer?

	Yes	No				
A personal visit to your employer by a staff member of the practice			V167			209
By means of a brochure giving general information regarding your treatment			V168			210
A telephone call to your employer to give general information			V169			211

3.20 Is your general financial position influenced by your hospitalisation?

Yes		V170		212
No				

3.21 To what extent was your medical aid influenced by your stem cell transplant?

My medical aid paid all costs	Yes	No	V171			213
My medical aid is exhausted after the stem cell transplant	Yes	No	V172			214
I had to make extra payments	Yes	No	V173			215
I am a private patient and am responsible for my own costs	Yes	No	V174			216

22 How do you see your future?

	V175		217
	V176		218
	V177		219
	V178		220

3.23 Is there anything else that you would like to draw our attention to?

	V179		221
	V180		222
	V181		223
	V182		224

THANK YOU FOR YOUR CO-OPERATION!!!

BYLAAG C:

INGELIGTE TOESTEMMING WAT DEUR RESPONDENTE VOLTOOI IS

UNIVERSITEIT VAN PRETORIA
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2001-06-25

Participants Name ______________________________ **Date** ______________

Principal Investigator

Hannetjie Opperman
Mary Potter Oncology Center
Little Company of Mary
Pretoria

Informed Consent

1. **Title of study**
"Die belewenis van'n beenmurgoorplantingspasiënt, 'n maatskaplike werk perspektief."
" The experience of a bone marrow transplant patient: a social work perspective".

2. **Purpose of study**
The purpose of this study is to investigate psycho-social impact of a bone marrow transplant on a patient.

3. **Procedures**
I will asked the patient on his/her first visit to the oncologist after his/her disharge from the hospital, after bone marrow transplant procedure, to fill in a questionare of 14 pages. The questionare will take approximately 20 munutes to fill in.

4. **Risks and discomforts**
There are no known medicial risks or discomforts associated with this project.

5. **Benefits**
I understand there are no known direct benefits in my participating in this study. However, the results of the study may help researchers gain better understanding of how patients experience bone marrow transplants and thereby improve service rendering.

6. **Praticipants Rights**
I may withdraw from participating in the study at any time.

7. **Financial Compensation**
No reimbursement of any kind will be paid to respondents. Partaking in the interviews is voluntary.

8. **Confidentiality**
In order to record exactly a questionaire will be profided by the Principal Investigator. The results of this study will be refelected in a research report and will be published in professional journals or presented at professional conferences, but the identity of the respondents will not be revealed unless required by law.

9. If I have any questions or concerns, I can call Hannetjie Opperman at (012) 346 6701 or cell no. 083 306 4489 any time during office hours.

I understand my rights as a research subject and I voluntarily consent to participation in this study. I understand what the study is about and how and why it is being done. I will receive a sighed copy of this consent form.

______________________________ ______________________

Subject's Signature **Date**

____

Signature of Investigator

BYLAAG D:

ETIESE KOMITEE GOEDKEURINGVAN DIE UNIVERSITEIT VAN PRETORIA

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Departement Sielkunde

2001-08-14

Mev J A Opperman
Posbus 32797
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0010

Geagte Mev Opperman

AANSOEK OM ETIESE GOEDKEURING VAN NAVORSING

Die navorsingsetiekkomitee het die ontbrekende stukke ter ondersteuning van u aansoek vir navorsing vir die MA (MW)-graad, in ontvangs geneem. U aansoek voldoen nou aan al die vereistes en word goedgekeur.

Graag wens ek u net die beste toe vir die uitvoering van u navorsing.

Vriendelik die uwe

....

Prof D Beyers
VOORSITTER : NAVORSINGSETIEKKOMITEE

cc. Dr C L Corbonato
Departement Maatskaplike Werk

UNIVERSITEIT VAN PRETORIA
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Studenteno: 9335021
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Afskrif aan: Dr CL Carbonatto
Afskrif vir u inligting

19 November 2001

Me JA Opperman
Posbus 32797
GLENSTANTIA
0010

Geagte me Opperman

STUDIERIGTING: MA (Maatskaplike Werk)

Met genoeë deel ek u mee dat die volgende goedgekeur is:

ONDERWERP: **Die emosionele belewenis van 'n beenmurgoorplanting: 'n maatskaplikewerkperspektief**

LEIER: **dr CL Carbonatto**

MEDE-LEIER:

U aandag word in besonder op die volgende gevestig:

1) **TERMYN VAN REGISTRASIE**
U moet vir minstens een akademiese jaar as student vir die magistergraad geregistreer wees voordat die graad toegeken kan word.

2) **JAARLIKSE HERNUWING VAN REGISTRASIE**
U registrasie moet jaarliks aan die begin van elke akademiese jaar hernu word totdat u aan al die vereistes vir die magistergraad voldoen het. Geen herregistrasie sal na 31 Maart aanvaar word nie. U sal slegs geregtig wees op die leiding van u leier indien u jaarliks bewys van registrasie aan hom voorlê.

3) **TYE VAN INDIENING VAN VERHANDELING/SKRIPSIE**
Word jaarliks in die kalender aangedui.

4) **GOEDKEURING VIR INDIENING**
Vir eksamendoeleindes moet u minstens voldoende eksemplare vir elke eksaminator indien tesame met 'n skriftelike verklaring van u leier dat hy die indiening van die verhandeling goedkeur. Die verklaring is by die Fakulteitsadministrasie beskikbaar. 'n Bedrag van R45 ten opsigte van mikroverfilming moet by indiening van die verhandeling/skripsie by die kassiere betaal word.

5) **ADDISIONELE EKSEMPLARE VAN DIE VERHANDELING/SKRIPSIE**
Afgesien van die eksameneksemplare, moet 'n kandidaat nog een gebinde eksemplaar en een ongebinde hoëkontras A4-eksemplaar vir mikroverfilming indien. Die twee addisionele eksemplare moet minstens een maand voor die promosieplegtigheid by die Fakulteitsadministrasie ingedien word, in gebreke waarvan die graad nie by die betrokke plegtigheid toegeken sal word nie. Hierdie eksemplare mag ook gelyktydig met die eksameneksemplare ingedien word.

6) **VOORSKRIFTE IN VERBAND MET DIE VOORBEREIDING VAN DIE VERHANDELING/SKRIPSIE ASOOK DIE SAMEVATTING IS OP DIE KEERSY VAN HIERDIE BRIEF UITEENGESIT.**

Die uwe

namens DEKAAN : GEESTESWETENSKAPPE

KANTOOR VAN DIE DEKAAN
FAKULTEIT GEESTESWETENSKAPPE
OFFICE OF THE DEAN
FACULTY OF HUMANITIES
2001 -11- 29
UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
PRETORIA 0002

GW-505

BYLAAG E:

“CHECKLIST” VIR PASIëNTE, FAMILIES EN DIE MULTI-DISSIPLINêRE SPAN VOOR DIE AANVANG VAN DIE BMT

Getting Ready for Your Stem Cell Transplant
A Patient Checklist

This checklist is a guide to help you prepare for your stem cell transplant. Some items will not relate to your situation. Although the list is long, please do not let it overwhelm you. You may use this list to help you develop questions for your transplant center coordinator, social worker or financial worker.

Self dvocacy

☐ Ask your doctor about how long he/she thinks you will need to stay at the Transplant Center. Identify someone to be present to assist you during and after your inpatient stay at the Transplant Center. This could include immediate family members or friends. They are commonly designated as your "caregiver" because they help with your follow-up care. Transplant Centers expect you to have a caregiver to stay with you after discharge.

☐ To help your caregiver in understanding his/her role, ask your physician what is expected of the caregiver. How long will you need a caregiver? When do they need to be with you? What types of activities will they be asked to perform? Could more than one person serve as a caregiver?

☐ Identify what works best for you to understand information regarding your upcoming treatment. You may want things explained in writing or you may want to have a friend or family member present to hear information with you. A tape recorder is an option if you want to play back important information later.

Choosing a regiver

☐ Sometimes you don't feel that you have a choice in who will be your caregiver. If you have more than one option, ask yourself how comfortable he/she feels in the hospital/clinic setting.

☐ Does your caregiver have the patience needed to wait for long periods (i.e., for procedures or doctors' visits)?

☐ Are you and your caregiver able to resolve differences?

☐ Will your caregiver understand your health care choices?

☐ Are there a number of support people within your family/friends network that could rotate the caregiver role?

☐ Is your caregiver able to get Family Medical Leave for an extended absence from work?

☐ If your caregiver is a spouse or significant other, discuss the ways in which your relationship might change after the transplant. You will have to depend on him or her more for help with your care. That can put a strain on the relationship.

Ongoing dical are

☐ Reschedule routine dental and medical appointments for you and your caregiver so they do not conflict with your transplant schedule. If your caregiver takes medications, he or she will also need to plan for getting them renewed if you are going to be far from home.

☐ If you or your caregiver are under a specialist or therapist's care, discuss the care plan to follow while away and arrange for possible follow-up care near the Transplant Center. Ask your current doctor what you should do if you need professional care while you are in another city or state.

amily nd riends

☐ Set up family meetings to talk openly about the transplant and the plans yo and your family need to make.

☐ If you have children or grandchildren, explain to them in words they can understand why you are going to the Transplant Center. You may use books, photos or videos to help them understand.

☐ Talk to your children about what will happen to them while you are in the hospital. Identify who will be with them, how their schedules will be kept and how you will communicate with them if you are separated. If you want assistance in talking to a child, contact your hospital social worker or child specialist.

☐ Discuss your own needs and concerns with your spouse, partner or significant other.

☐ Consider setting up an appointment with a counselor to assist you and your family to prepare for transplant.

☐ Participate in a send-off gathering with family and friends. Have pictures taken to bring with you.

☐ If friends and family want to know how they can help or what they can send, consider long distance calling cards, snacks, meal certificates, notes of encouragement, videos of family and friends.

nding upport

☐ Children may benefit from being connected to others in their age group who also have a family member being treated for cancer. The American Cancer Society and the Leukemia and Lymphoma Society have children's groups in many locations. Your local hospital social worker may refer you to other groups. Kids Konnected offers a Web site (www.kidskonnected.org) or toll-free line (1-800-899-2866) with simple instructions to aid in talking with children about cancer.

☐ Support groups for adults or family members often help during stressful times by providing answers to commonly asked questions and mutual support from others who have been in similar circumstances. Contact the local hospital, American Cancer Society or Leukemia and Lymphoma Society to find out what is available near you.

☐ Talk honestly with friends, families and colleagues to help them understand the types of support that will assist you and your family during this difficult time period.

☐ Support comes from many sources. Reach out to work colleagues, neighbors, community organizations, religious or spiritual groups, extended family or supportive friends. A group may offer to provide meals for family members at home while you are at the hospital. Others may offer to provide rides for children to school activities.

☐ Online support can be found for information, connecting with transplant survivors or talking electronically with others. (For example: www.bmtinfonet.org). Remember that medical opinions shared by others or information received over the Internet does not substitute for advice given by your doctor or Transplant Team.

inancial

☐ Veterans should contact their Veteran's Administration office to inquire if they are eligible for any programs based on their service record and their disability.

Financial, ont.

☐ Fundraising may be done locally on your behalf. You may want the experienced advice of a fundraising organization if you anticipate uncovered medical expenses (National Foundation for Transplants, 1-800-489-3863, or The National Transplant Assistance Fund, 1-800-642-8399).

☐ Some organizations offer limited financial assistance to help with costs not covered by insurance. For example: Leukemia and Lymphoma Society (for patients with leukemia, lymphoma or multiple myeloma), 1-800-955-4572 or contact your local chapter; Cure for Lymphoma Foundation (for patients with Hodgkin's disease and Non-Hodgkin's Lymphoma), 1-800-235-6848. Check with your Transplant Center for additional resources.

☐ The Federal government has two income insurance programs available for adults: Social Security Disability and Supplemental Security Income. Eligibility is based on a determination by your physician that your disability will last one year or longer. You may qualify to start receiving benefits at an earlier date and you should contact Social Security to apply (1-800-772-1213 or www.ssa.gov). Those who qualify for Supplemental Security Income (based on meeting minimum income requirements) will also be eligible for Medicaid that can help cover medical care.

☐ Keep extra checks, deposit slips, and your ATM/debit/cash card on hand. Make sure you and your caregiver know your PIN number in case you need to access cash from an automated teller machine (ATM). Do not store these things in your hospital room or hotel room. Your caregiver should keep them on their person in a purse or wallet.

Employment

☐ Contact your employer to make arrangements regarding absence from work. Seek out your employee Human Resources Representative to help you understand your benefits and responsibilities in order to qualify for disability and continuation of insurance. Know your rights regarding COBRA insurance benefits, work disability and Family Medical Leave.

☐ If you are covered under your employer's disability plan (short and/or long term), the employer will assist you in determining when to apply for Social Security Disability..

gal

☐ Many employers have employee assistance programs that include access to legal advice. You may be interested in completing a will, a trust, planning guardianship (if you are a single parent), completing a living will or designating power of attorney. If you do not share joint checking accounts, you may want to designate someone to handle your financial affairs temporarily.

☐ Depending on how complicated your financial or legal affairs are, you may want to consult a financial or family law attorney. Contact your local bar association for referral to someone who practices this area of law.

☐ If your minor children will be separated from both parents, you need to give permission for another adult to take them for medical care (emergency or routine) in your absence. Generally, a signed statement will suffice, but you should check this out with your child's doctor.

avel nd dging

☐ Ask your Transplant Center contact about lodging resources near the transplant center. Ask for costs and whether you need to put your name on a waiting list. The National Association of Hospital Hospitality Houses, Inc. may also list lodging options in the area. Call 1-800-542-9730.

Travel, cont.

☐ Check with your insurance company to see if your benefits cover travel, m and lodging for yourself and a caregiver.

☐ Make travel arrangements. You may want to ask family members if they have frequent flyer miles available to assist you. If you need assistance for travel, you may contact the National Patient Travel HELPLINE Program at 1-800-296-1217 for resource information.

☐ AirLifeLine offers free trips on small planes for distances less than 1,000 miles for patients who meet medical and financial guidelines. Call toll free at 1-877-AIR-LIFE for more information.

Faith and pirituality

☐ If consistent with your beliefs, arrange ways to keep in touch with your faith community. Other members may want your address to send cards and give encouragement.

☐ Many faith communities have rituals for healing or have other important ways of offering support. You may want to discuss this with your faith leader.

☐ There may be connections to your faith community in the city where your transplant will take place. You may want to make a local contact for additional support.

Before Leaving Home

☐ Prepare a packing list. Think of clothes for different temperatures and seasons, if appropriate. Include some family photos or posters that may brighten your hospital room or temporary living space.

☐ Bring phone lists, addresses, e-mail directories and a phone card to use for long distance calls while you are away from your home phone.

☐ Arrange how your home or apartment will be looked after while you are away.

☐ Consider how bills will be paid in your absence. When possible, pay ahead. You may consider checking with certain loans (such as car, student loan, etc.) about the possibility of temporary deferment (grace period) of payments due to medical disability.

☐ Have your mail forwarded or arrange to have someone collect your mail for you while you are away.

☐ Make arrangements for someone to care for your pet during your intensive treatment. Most temporary lodging facilities do not have accommodations for pets.

NATIONAL MARROW DONOR PROGRAM®

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Getting Ready for Home

A Checklist of Questions to Ask Your BMT Health Care Team

When you leave the hospital after your transplant, you will receive information about when to call the octor to report a fever, how to take medications, and who to call for emergencies. You will see your MT clinic doctor often while your new stem cells are growing.

The next step is leaving the Transplant Center and returning to your regular doctor. For many people, he Transplant Center is far from home. What information should you take with you when you leave? Ve hope the following questions and general guidelines will help you prepare for this transition.

This checklist contains only general guidelines. Your Transplant Center may have more specific guidelines for u to follow. Check with your BMT doctor or nurse coordinator for specifics regarding your situation.

☐ *CONTINUING MEDICAL CARE*

Q: *What medical information has been sent to my regular doctor? Does he or she know who to call with questions about my transplant?*

A: A letter is generally sent by the Transplant Doctor to your regular doctor with a summary of your transplant course. Some doctors will also call. Your doctor will be given information on how to contact the BMT team. He or she will also be told what symptoms to look for, such as a new onset of graft versus host disease (GVHD). The complete medical record does not need to be sent.

Q: *What information should I carry with me?*

A: You may ask for copies of the most recent notes and test results to hand carry to your doctor. You should always have a list of your current medications and doses with you. Keep basic records for yourself for your future medical care.

Q: *When should I or my regular doctor call the Transplant Doctor for advice? What symptoms are serious enough that I would have to go back to the Transplant Center for more follow-up care or tests?*

A: If your GVHD symptoms get worse, or if you develop GVHD, you should talk to your Transplant Doctor or nurse. Your Transplant Team may recommend a change in treatment.

Q: *What are the warning signs of chronic GVHD?*

A: Sores in the mouth and pain or grittiness in the eyes. Other signs include being sensitive to light, nausea/vomiting, trouble swallowing, shortness of breath, persistent dry cough, numbness, tingling and weakness.

Q: *Should I wear an ID bracelet to let people know I have had a stem cell transplant and might need special care?*

A: An ID bracelet is optional, but it is a good idea. The information would tell people that you have had an unrelated stem cell transplant and that you should only receive irradiated blood products.

Q: *In my case, I still need to have blood products and antibiotics regularly. Who will arrange this for me?*

A: Your BMT nurse or doctor communicates directly with your home doctor and an appointment is scheduled as soon as possible when you return. If needed, a home care nursing visit may be arranged.

❐ *PREPARING THE HOME ENVIRONMENT*

Q: *How do I need to prepare my home?*

A: Keeping the home clean is important. You should not do the dusting or vacuuming, or be in the room when dust is in the air. Do not have any remodeling work done on your home at this time.

Q: *Can I still care for my pets?*

A: It's okay to be around pets that you had before your transplant. Check with your doctor about birds or reptiles, though. Let others do pet care such as grooming or waste removal. It is not a good idea to bring home a new pet during the first year after transplant.

❐ *EDUCATING VISITORS*

Q: *How do I teach people what they need to do before they come to visit?*

A: It's often hard to set limits with visitors outside of the hospital without hurting their feelings. Explain to friends and family that your doctor gave rules for your protection and this may help them understand. Hand washing is the best way to keep infections from spreading.

Q: *How long do I enforce hand washing rules?*

A: Good hand washing should be maintained at all times, especially before preparing food, after going to the bathroom and after playing with pets.

Q: *Should there be a limit to the number of people in the room when we are at home?*

A: Smaller groups are better.

Q: *When should masks be worn in the house? (by visitors or family)*

A: Ask your Transplant Center for specific guidelines. Generally, masks are not worn at home.

❐ GETTING BACK TO NORMAL

Q: *When does life return to normal?*

A: When you return home, life doesn't return to normal right away. Just as life changed when you got sick, it will change again as you become stronger. You'll gradually want to start taking on the tasks you did before. It's important to continue to talk about changes with your family and friends.

Q: *What types of social activities do I need to stay away from for the next few months? When can I get back to more normal social activities?*

A: Your immune system is still recovering during the first year after an allogeneic stem cell transplant. When your white count is low (ANC less than 1000) or you are taking medicine that suppresses your immune system, you should stay away from enclosed, crowded places. If planning to eat out or go to a movie, choose a time when it is not busy.

Q: *When may I resume sexual activity?*

A: While you are healing, your interest in sexual activity is often low due to lack of energy and not feeling well. Resuming sexual activity is a normal part of recovery, but each person must take it at his or her own pace. For women, the platelet count should be above 50,000 and **absolute neutrophil count, (ANC)** of 1000, due to the risk of bleeding or infection. If you have other questions or worries, you should discuss them with your doctor or nurse. There are many ways to remain close to your partner, such as holding hands, snuggling or sitting close and spending time together doing things you both enjoy. The American Cancer Society offers resources for men and women that deal with sexuality and cancer. Resources are available online at www.cancer.org.

Q: *When will my energy level improve? When will my counts be more in the normal range? How do I tell the difference between my physical recovery from the transplant and a new problem?*

A: People get their energy back at different times, some sooner than others. It's normal to take lots of naps. Patience is needed as your energy will return slowly. If you are taking medication for GVHD, your immune system and energy level will not recover as quickly. Any major energy level change should be reported to your doctor. It is normal to feel good one day and overdo activity, making you tired the next day. Try to save your energy by doing moderate amounts of activity.

❑ *BACK TO WORK*

Q: *When may I go back to work? (What should I tell my employer about how long I will be out on disability?)*

A: Ask your physician about the estimated length of your disability. You may qualify for Social Security Disability or Supplemental Security Insurance. Your Human Resource Representative at work or the hospital social worker can help you understand how these programs may apply to your situation.

Q: *What are my rights concerning disability and how long will I be able to keep my job and my insurance coverage?*

A: Contact your employer regarding extended absence from work. Seek out your employee Human Resource Representative to help you understand your benefits and responsibilities in order to qualify for extended disability and continuation of medical insurance.

Q: *When I am ready to return to work, what can I do if I feel I'm being discriminated against based on my medical history?*

A: Under federal law and many state laws, an employer cannot treat you differently than other workers based on a medical diagnosis if you are qualified for the job. To understand your rights, contact the National Coalition for Cancer Survivorship for information and publications. Call toll-free 877-622-7937 or visit the website www.can search.org.

☐ *BACK TO SCHOOL*

Q: *When can a child return to school following a stem cell transplant?*

A: Children may return to school from six months to a year after transplant. It depends on the recovery of your child's immune system and physical strength. Until then, you can make plans with the school to keep your child involved in his or her schoolwork. Your child may be eligible for special programs through school. When it is time to go back to school, contact your hospital social worker, nurse or school counselor for resources such as videos, written materials and other ideas to make going back to school easier for your child.

☐ *EXERCISING*

Q: *How much exercise is safe? Can I go swimming? Horseback riding? Skiing? If not now, when?*

A: Exercise should be gentle and done in moderation. When your platelets are low, falls can result in serious bleeding. Walking is one of the best forms of exercise at this time. Consult your doctor before resuming rigorous exercise. You can't swim until your central line is removed and has healed. Swimming pools can be an easy place to pick up infections. Postpone all these activities for several months until your doctor feels that you are ready.

Q: *When can I work in the garden or yard?*

A: Wait six months to one year before digging in the dirt or mowing the lawn. This is the year to sit in your favorite outdoor area or take leisurely walks. It's best to wear your mask on windy days when there may be dust or dirt in the air.

☐ *DEALING WITH EMOTIONS AND FINDING SUPPORT*

Q: *What types of support will I need when I return home?*

A: Often when you first get home, you find you are still in need of a support network, but those you may have counted on in the past may not know this. There will still be times when you can not be alone or need assistance during the day. There will still be many doctor appointments and transportation needs. Caregivers who return to work may find that they are stretched to the limit and that a support system is needed more than ever. The positive side is that home is where your family and friends are located. It's time to get back in touch and ask for help.

Q: *Where can I find a support group to fit my needs?*

A: Ask for referrals from social workers or local resources such as the American Cancer Society or Leukemia and Lymphoma Society. (Those with computers may check www.cancercare.org or call 1-800-813-4673 for options such as online or telephone support.) Talk honestly with family and friends to help them understand the types of support that you find helpful after transplant

Q: *What kind of support is available for caregivers?*

A: Look for caregiver support groups. While these groups may have a variety of caregiver issues, most caregivers will find they have many common concerns.

Q: *How can I work through the changes in my physical appearance?*

A: Your body may have gone through many changes following BMT. These may include hair loss, weight gain or loss, puffy face due to steroids and changes in skin condition from GVHD. You may have scars from procedures such as your central line. Most changes are temporary. A support group or counselor could be helpful as you deal with your feelings.

Q: *Sometimes it feels like I've been through a war. How do I process all that I've been through?*

A: This may be the time to talk through your experience with a therapist. Different issues may come up at different times, even one year or several years after the transplant

Q: *I am glad to leave the Transplant Center and be through this part of treatment, but I am very scared about what's going to happen next? Who can I talk to? Do others feel the same way? Why does everyone expect me to be happy?*

A: You may find that you have a need to talk with others in similar situations. There are organizations that can connect you with another BMT survivor. Online support can be found for information, connecting with transplant survivors by phone or by e-mail with others. (Contact www.bmtinfonet.org or call 1-888-597-7674 toll free.) Some people find the need to talk to a professional counselor who has treated post traumatic stress disorder or has worked with people who have health-related trauma.

☐ *TALKING WITH FAMILY*

Q: *What concerns might my family have when I return home?*

A: Returning home is a happy time, but problems that existed before the transplant may now resurface. Communication is more important than ever. Some family members will want everything to return to the way it was before transplant, but recovery is still a long road ahead.

Q: *Are children going to have specific concerns?*

A: Children who have had alternate caregivers may need time to adjust to being together again as a family. Children may need to test rules and may show anger. Trust between parent and child needs to be rebuilt. Be patient and realize that it will take some time to settle into the new routine.

☐ *BEFORE GOING HOME (WHEN YOU LIVE IN A DIFFERENT TOWN)*

Q: *What other issues I should think about before leaving the Transplant Center?*

A: If you rented an apartment during your transplant stay, there are often several chores to take care of before you leave. Do you need to cut off your phone service? Have you told your apartment management that you are leaving? Have you forwarded your mail?

Q: *There are many people that I have formed friendships with during the past several months. Will I want to stay in touch?*

A: Say your goodbyes to important people with whom you have connected during the past months. You may want to exchange addresses with other families that you have come to know.

☐ *TRAVELING*

Q: *When should I avoid travel by plane? (Is this dependent on my platelet or white counts?)*

A: Many people plan to return to their home by airplane. Discuss this with your doctor before making your travel arrangements. Pressurized cabins in airplanes have air that is recirculated, allowing germs to spread.

☐ *FINDING FINANCIAL INFORMATION*

Q: *If my work disability is coming to an end, are there other programs that provide income?*

A: The federal government has two income insurance programs available for adults: Social Security Disability (SSD) and Supplemental Security Income (SSI). Eligibility is based on a disability determination by your physician that your disability will last one year or longer. SSD is based on money you have paid in to Social Security through payroll tax. SSI is a program for people (including children under 18) who are disabled and have limited income and resources. You may already qualify to start receiving benefits based on income or date of disability. Contact Social Security as soon as possible to apply. If you are covered under your employer's disability plan (short and/or long term), the employer will assist you in deciding when to apply. Those who qualify for Supplemental Security Income (based on meeting minimum income requirements) may also be eligible for Medicaid that can help cover medical costs. Social Security 1-800-772-1213 or www.ssa.gov.

Q: *I'm a Veteran. Do I qualify for additional income?*

A: Veterans should contact their Veteran's Administration office to inquire if they are eligible for any programs based on their service record and their disability.

☐ *THINKING ABOUT LONG TERM EFFECTS*

Q: *What are the long term effects of stem cell transplant?*

A: Long term effects could include disease relapse, secondary malignancy (cancer), cataracts, infertility, ovarian failure, short term memory loss and numbness or tingling of the feet or hands. Some of these might not surface until years after your transplant. Make sure you tell your doctor if you have any of these effects. If you are having a relapse, early detection will make it much easier to treat.

Q: *How can I deal with dry eyes and dry mouth?*

A: Use artificial tears (eye drops) for eyes and suck on hard candy for dry mouth. Drink plenty of fluids.

Q: *What are some of the signs of depression? I have heard that some people suffer from "post-traumatic stress syndrome." How can I recognize if I have a serious emotional problem?*

A: Many of the signs of depression are similar to symptoms of medical problems such as difficulty eating or irregular sleep patterns. It is always good to first check with your medical doctor to rule out any physical problems associated with your treatment. If you are unable to concentrate, feel overly emotional or as though you lack emotions and have been feeling unhappy for several weeks, you may need to consult a counselor and psychiatrist to see if you are suffering from depression or a related disorder. There are medical treatments to help and talking with a counselor can also assist your recovery.

Q: *What should I know about long term effects of transplant regarding children?*

A: If transplant occurs before puberty, a child may not reach sexual maturity. If the stem cell transplant occurs before age 10, there may be concerns about achieving normal growth or experiencing difficulty in school. There are many interventions that can assist parents in helping their children manage these late effects. Starting early is important in dealing with these concerns. (Recommended reading: *Childhood Cancer Survivors: A Practical Guide to Your Future* by Nancy Keene, Wendy Hobbie & Kathy Ruccione.)

Q: *Sometimes it's difficult to be a BMT survivor. What can I do with the experience I've gained?*

A: Many caregivers, parents and patients want to do something with the hard won knowledge they've gained from their experience. There are many organizations that look to transplant survivors to share their experiences with others who are just starting out. For more information, contact your hospital social worker or any of the organizations that are listed in this checklist for ideas in how to share your transplant journey with others.

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BYLAAG F:

"CHECKLIST" VIR VERSORGERS VOOR DIE AANVANG VAN DIE BMT

Getting Ready for Your Child's Stem Cell Transplant
A Parent's Checklist

This checklist is a guide to help prepare for your child's stem cell transplant and stay at a Transplant Center. Although the list is long, please do not let it overwhelm you. Some of the suggestions may not apply to your circumstances and others will help you to think of preparations not listed. This list is not all-inclusive. Please contact your hospital social worker if you need assistance or clarification.

atient

- ☐ Talk honestly with your child about the hospital stay and change in location (if changing hospitals or cities), explain in words that your child will understand. You may use books, videos or pictures to help tell the story.
- ☐ Talk with your child about the plan. You may include details of how you will travel, who will be coming along, what will happen with siblings, pets who will be staying home.
- ☐ Talk with your child (in words they will understand) about what will happen upon your arrival at the Transplant Center. You may include information about where you will be living, where he or she will receive medical care, and what the schedule will be like.
- ☐ Reassure your child that Mom, Dad or identified caregiver will be with him or her and will help with whatever needs the child has.
- ☐ If you want or need help in talking with your child, ask your social worker, teacher, school counselor or child specialist at your local hospital.
- ☐ Help your child to make a list of items he or she would like to take along.

mily Members d Caregivers

- ☐ Make necessary arrangements with your employer for your absence. Utilize paid or unpaid leave of absence. Talk with your employer or Human Resources Department about the Family Medical Leave Act.
- ☐ You may consider maintaining some level of paid work if possible by using telephone, fax or computer.
- ☐ Arrange how your home will be looked after while you are away.
- ☐ Consider how bills will be paid in your absence. When possible, pay ahead.
- ☐ Have your mail forwarded or arrange to have someone collect your mail for you while you are away.
- ☐ Discuss your own needs and concerns with your spouse, partner or significant other.
- ☐ If you are a single parent with more than one child, you may want to discuss legal arrangements for your other children if you go out of state for your child's treatment. An important consideration is who will be able to give consent for medical treatment while you are away. Discuss this with your child's doctor and other involved parties.

Family Members and Caregivers, cont.

- ☐ Begin to think about ways you can take care of yourself so that you will be better able to care for your child.
- ☐ Complete your own routine physical and dental appointments if due in the near future.
- ☐ Make sure you refill your own prescriptions if needed. Make sure you will be able to have prescriptions refilled while you are away from home.
- ☐ If you are under a physician's or therapist's care, discuss the care plan you will follow while out of state. Arrange if necessary for medical or psychological care at or near your Transplant Center.
- ☐ Consider having a family photograph taken. Bring a copy along and leave a copy with any family members (such as siblings or grandparents) at home.

blings

- ☐ Talk with your children to tell them what will be happening within the family while their sibling is going through a stem cell transplant. It is important to be honest and use words that your children will understand.
- ☐ If children are staying at home, talk with them about who will take care of them. Reassure them they will be taken care of during this time and that you love them. Tell them you will make plans for all the family members.
- ☐ Discuss if there will be planned family visits to the Transplant Center.
- ☐ If siblings are coming along, talk with them about who will take care of them. Prepare children that different friends or family members may be taking turns caring for them while you are caring for their brother or sister.
- ☐ School enrollment may be available at the hospital, Ronald McDonald House or in the community. Talk with your Transplant Center social worker to see if this is available.
- ☐ Talk with your child's teacher/principal about the plan of absence and ways to keep your child connected with the school both academically and socially.
- ☐ Bring your child's books and assignments along to the Transplant Center.
- ☐ Bring the school's address, telephone number and teacher's name.

nor

- ☐ If a sibling is your child's donor, talk with him about his role, explain what his schedule will be.
- ☐ You can tell the donor that his or her body will create new stem cells to replace the ones that are harvested for transplant.
- ☐ It is important for the donor to understand that he has done a wonderful thing in donating marrow but that he is not responsible for the final outcome.
- ☐ There are emotional aspects of donating marrow to a loved one and it sometimes is helpful for the donor to talk to a counselor or social worker.

Faith and irituality

☐ If it is consistent with your beliefs, consider informing your faith leader and community of your temporary address. You may wish to establish a plan of communication (e.g., e-mail, cards, visitation, telephone tree for information updates) with them.

☐ You may ask your faith leader/community to offer special prayers, healing/anointing services and/or other healing rituals for you and your family before leaving for the Transplant Center.

☐ Provide a time and opportunity to talk with your family about what each of you believe. Consider talking about what gives you comfort and strength as you and your family prepare for your child's stem cell transplant.

avel nd dging

☐ Make travel arrangements. You may want to ask family members if they have frequent flyer miles available to assist you. If you need assistance for travel, you may contact the National Patient Travel HELPLINE Program at 1-800-296-1217 for resource information.

☐ AirLifeLine offers free trips on small planes for distances less than 1,000 miles for patients who meet medical and financial guidelines. Call toll free at 1-877-AIR-LIFE for more information.

☐ Check with the Ronald McDonald House near your transplant center to see what prior arrangements can be made.

☐ Ask your Transplant Center contact about lodging resources near the Transplant Center. Ask for costs and whether you need to put your name on a waiting list. The National Association of Hospital Hospitality Houses, Inc. may also list lodging options in the area (1-800-542-9730).

inancial

☐ Check with your insurance case manager to learn if there is coverage for your housing, travel and meal expenses related to your child's stem cell transplant.

☐ If you receive medical assistance via your county, talk with your caseworker about financial assistance for travel, housing and meals for patient and caregiver.

☐ You may consider participating in fundraising activities for uncovered expenses related to bone marrow transplant. If you receive Medicaid or Supplemental Security Income, talk to your caseworker or home hospital social worker about how to process any money that is raised so that it does not affect your eligibility for medical assistance or state funded disability support.

☐ Keep extra checks, deposit slips, and your ATM/debit/cash card on hand. Make sure you know your PIN number in case you need to access cash from an automated teller machine (ATM). Do not store these things in your hospital room or hotel room. Keep them with you in a purse or wallet.

amily and riends

☐ Participate in a send-off gathering with family and friends.

☐ If friends and family want to know how they can help or what they can send, consider long distance calling cards, snacks, meal certificates, notes of caring and encouragement, videos of family and friends, and items that you and/or your child might enjoy.

Communication

- ☐ Plan for how you will stay in touch with family members and friends back
- ☐ Bring long distance telephone cards.
- ☐ Bring telephone/address directory and e-mail addresses.
- ☐ Consider using video or audiotapes to maintain contact with separated siblings or parents.

Packing List

- ☐ Make your own packing list as you think of items you want to bring.
- ☐ Think of small personal belongings to bring that are a source of comfort to you and your child.
- ☐ Consider bringing photos of home, pets, family and friends to decorate the hospital room or your temporary housing.
- ☐ Pack clothing items for changing seasons and temperatures, if appropriate.

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BYLAAG G:

DIE HEMOTOLOGIESE EN BEENMURG OORPLANTINGS PSIGO-SOSIALE EVALUASIE

Blood and Marrow Transplant
Initial Psychosocial Assessment

Patient Information:

Patient Name: ______________________________ Date: __________
Address: ______________________________
City: ____________________ State________ Zip:______
Phone: ____________ Alternate Phone # ____________

DOB: __/__/__ Age: ___ Gender ___M ___F Race:________
Marital Status: M__ D__W __S
Name of Spouse ______________________________
Name and ages of Children ______________________________
____
____

Patient is being considered for an
____ Autologous ______ Peripheral (stem cell transplant)
____ Allogenic ______ Bone Marrow
_____ Related
_____ Unrelated

Diagnosis: ____________________ Date of diagnosis ______________
Physician: ____________________
Pharmacy: ____________________ Phone: _(_____)______________

Patient's Financial/Health Resources

Employment	___ Pt	___ Spouse	$	____________
Social Security	___ Pt	___ Spouse	$	____________
SSI/SSDI	___ Pt	___ Spouse	$	____________
Food Stamps	___ Pt	___ Spouse	$	____________
Pension/VA	___ Pt	___ Spouse	$	____________
Work/Other	___ Pt	___ Spouse	$	____________
Total Income for month			$	____________

Health Insurance ______ Medicare ______ Medicare Supplement ______Medicaid
______ Commercial ______ Other:______________
Medications Covered ___ Yes ___ No If not, cost of medications/month: __________
Mthly expenses ______________________________
Income adequate to meet patient needs: ______________________________

Advanced Directives: (Make sure to get copy for chart)
Living Will: ___Yes ___ No
Power of Attorney HC: ___Yes ___ No Person ______________Relationship __________
Pre-hospital DNR ___ Yes ___ No
DNR Status ______________________________

Legal Problems/Concerns: Is pt currently involved with the legal system _____ If YES, please note how and how this will impact treatment plans: ______________________________
____
____

Social and Emotional Factors Related to Patient's Illness and Need for Care:

Employment Status:
Is pt currently employed _____ If YES, then where ______________________________
How long __________ What type of work? _______________ Is employer supportive? __________
Is patient currently on medical leave? ______ Is pt aware of FMLA? _________ Is pt on COBRA? _________
Previous work Hx: ____
What, if anything, has the doctor said about return to work? ____________________
Has pt applied for disability? ______ Where are they at in this process? ________________

Living Arrangements:
Patient lives with: ___Alone ___ Spouse ___ Other (please note who) ________________
Patient home alone for extended periods of time due to: ____________________
Housing arrangement s during BMT : ______________________________
Patient's primary caregiver is self/other ______________________________
Pt's caregiver(s) for BMT process: (name, phone number) ____________________
____
____

Patient/caregiver limited in ability to comply with Plan of Care: ____________________
____

How long does it take for pt to get to the facility? __ less than 30 minutes__ less than 2 hours __ 2 hours or more
And how many miles one way? _____________

Pt's ambulatory status: ____
Does patient require assistance with ADLs : _____ If yes, please list ____________________
Patient relies on ________________to obtain food/to prepare meals/to obtain medication/for primary caregiving/ to handle finances/for transportation/for indoor/outdoor housekeeping. Please circle all that apply.

Patient has adequate supervision? ___ Yes ___ No Adequate Care? ___ Yes ___ No
Adaptive Equipment? ____Yes ___No. If YES, please list ________________________

Education: _______ Some high school _______ highest grade completed
_______ High school graduate
_______ Vocational/Technical Training
_______ Some College/Degree received/some post graduate/post graduate degree

Communication Skills ____Can verbalize needs ____ Non-verbal ____ Non-English speaking

Preferred method of receiving information: ______ reading/written ______audio ______ tapes
______ demonstration ______other (please describe) ____________________

Factors that impact learning: Please check all that apply.
_____ Hearing: ____ Adequate ____ Poor (hearing aid) ____Deaf
_____ Vision: ____ Adequate ____ Poor (glasses) ____ Legally blind
_____ Cognitive
_____ Difficulty reading/writing
_____ Physical
_____ None
_____ Other ______________________________

Mental Status: ____ Alert/Oriented x (   ) ____ Disoriented ____ Short-term memory loss
____ Forgetful ____ Lethargic ____ Labile ____ Unresponsive ____ Delusional thinking ____ Hallucinating
_____ Significant Dementia _____ Other: ______________________________

Emotional Status: ____ Stable ____ Positive ____ Angry/Hostile ____ Depressed ____ Withdrawn
____ Tearful ____ Feeling helpless/hopeless _____Anxious/ Overwhelmed ____Lonely/Isolated ____Suicidal
____ Other: ____

Family and Social Support Network:

Primary Caregiver: ____________ Relationship to the Patient: ____________
Address (if different from the patient) ____________
Phone ____________
Are they employed? ____ If YES, where? ____________ On FMLA? ____

Family's present behavior: ___ Cooperative ___ Open ___ Cohesive ___ Conflictual ___ Chaotic
___ Other: ____________

Support Systems: ___ Family ___ Friends ___ Church ___ Social Organizations ____ Work
Other: ____________
___ No support system in place

What are pt's hobbies and interests? ____________

Comments: ____________
____

Personal life style patterns:

Does pt have a mental health history? ___ yes ___ no If YES, please describe. ____________
____
(Diagnosis or history of depression/anxiety/or other mental health problems?)

Has pt Ever seen a counselor? ___ yes ___ no. If YES, please note when and for what? ____________
____

Is pt currently taking any medications for anxiety/depression/or other emotional concerns? ___ yes ___ no
If YES, list medications/dose/frequency and who prescribed and reason. ____________
____

Does pt use any drugs to self medicate for anxiety/depression,/sleeping problems/ or other? ___ yes ___ no
If YES, please list type/frequency/dose, etc. ____________

Is pt using any CAM? ___ yes ___ no. If YES, please describe ____________
____

Does pt/family member smoke? ____ Who ____________ How many packs per week ______
Does pt/family member drink? ____ Who ____________ How many drinks per week ______
Pt/family have/had hx of alcohol/substance abuse ____________

Spiritual/Religious Needs

Does pt belong to any denominational background? ____________
Name of Church ____________ Pastor/priest ____________
Is spiritual faith any important resource? ___ yes ___ no
Of your resources for coping, where would you rate your spiritual faith (on a scale of 1-10)? ________

Additional Questions for BMT

- What is the pt/family's understanding of the BMT process? ____________
  ____
- If children are involved, what is there understanding of your cancer dx and BMT? ____________
  ____
- What are the plans for them while you are going through BMT? ____________
- ____________
- What do you hope for as a result of this transplant? ____________

process? ____________________

- What is pt's philosophy of living with cancer or other life threatening illness? ____________________
- What motivates you? ____________________
- What would you tell another pt newly dx with cancer? ____________________
- How do you feel about being confined to a hospital for an extended period of time? ____________________
- How do you feel about being away from home during this process? (if applicable) ____________________
- What type of side effects have you had from previous treatments? ____________________
- What has helped you to reduce these? ____________________
- What concerns have you experience since hearing your diagnosis? ____________________
- Describe physical changes, emotional concerns, financial concerns, etc.? ____________________
- Have you experienced changes in your ability to carry out your usual activities? ____________________
- Were these changes due to physical or emotional factors or both or other? ____________________
- How are responsibilities divided in your home? (household tasks, child care, money mgt) ____________________
- Who in your family carries major decision making responsibilities? ____________________
- What process works best for you in reaching decisions? ____________________
- How are differences of opinion resolved in your family? ____________________
- Have you experience any significant losses in the past? ____________________
- What coping techniques/mechanisms do you or have you used? ____________________
- Who do you call upon for support? ____________________
- Do you have anyone close to you that has or had cancer? ____________________
- How could the staff be supportive of you? ____________________

Identified Problems/Needs of Patient and Family (check all that apply):

____ Caregiver for BMT
____ Health Insurance
____ Medication
____ Transportation
____ Support Group
____ Medicaid
____ Counseling
____ Volunteers

____ Lodging
____ Financial/Planning Assistance
____ Legal Services
____ Home Repairs
____ HomeCare services
____ Alternative Living Facility
____ Eye/Ear/Dental
____ Other: ____________________

____ Applying for Benefits (SSDI, etc.)
____ Sitters/Respite
____ Phone contact
____ Substance abuse
____ Lifeline
____ Budgeting
____ DME

Plan of Care

____________________ Signature

____________________ Date

BYLAAG H:

HADS (HOSPITAL AND DEPRESSION SCALE)

NAME / NAAM:.. **MALE/MANLIK** ☐

SURNAME / VAN:.. **FEMALE/VROULIK** ☐

MARITAL STATUS / HUWELIK STATUS: ....

DATE OF BIRTH / GEBOORTEDATUM: ....

NO OF CHILDREN / AANTAL KINDERS ....

LOCATION/VERBLYF:..**CITY/STAD/RURAL AREA/ PLATTELAND**

DIAGNOSIS / DIAGNOSE: ....

DATE OF TEST:
DATUM VAN TOETS: .... **DATE OF DIAGNOSIS:**
DATUM VAN DIAGNOSE: ....

ONCOLOGIST:
ONKOLOOG: .... **TELEPHONE. NO.**
TELEFOON NR: ....

Doctors are aware that emotions play an important part in most illnesses. If your doctor knows about these feelings he will be able to help more. This questionnaire is designed to help your doctor to know how you feel. Read each item and place a firm tick in the box opposite the reply which comes closest to how you have been feeling in the past week. Do not take too long over your replies. Your immediate reaction to each item will probably be more accurate than a long thought-out response.

Dokters weet dat emosies 'n belangrike rol by die meeste siektes speel. As jou dokter van hierdie gevoelens weet, sal hy jou beter kan help. Hierdie vrae is opgestel om jou dokter te help agterkom hoe jy voel. Lees elke item en maak dan'n kruisie in die blokkie langs die antwoord wat die beste beskryf hoe jy die afgelope week gevoel het. Moenie te lank oor jou antwoord dink nie. Jou eerste reaksie op elke item sal waarskynlik meer akkuraat wees as een waaroor jy lank nadink.

TICK ONLY ONE BOX IN EACH SECTION/
MERK NET EEN BLOKKIE IN ELKE SEKSIE

1
I FEEL TENSE OR "WOUND UP"/
EK VOEL GESPANNE OF "OPGEWEN"

Most of the time/ Meeste van die tyd..... ☐
A lot of the time/Baie kere................ ☐
ime to time, occasionally/ van tyd tot tyd
by geleentheid............................. ☐
Not at all/ Glad nie........................ ☐

2
I FEEL AS IF I AM SLOWED DOWN/
EK VOEL ASOF EK STADIGER OF DOOIERIG IS

Nearly all the time / Byna altyd........... ☐
Very often/ Baie dikwels.................... ☐
Sometimes/ Somtyds......................... ☐
Not at all/ Glad nie.......................... ☐

3
I STILL ENJOY THE THINGS I USED TO ENJOY/ EK GENIET STEEDS DIE DINGE WAT EK VROEÉR GENIET HET.

Definitely as much/Beslis soveel........ ☐
Not quite so much/Nie heeltemal nie... ☐
Only a little/Net 'n bietjie............... ☐
Hardly at all/Glad nie..................... ☐

4
I GET A SORT OF FRIGHTENED FEELING LIKE "BUTTERFLIES" IN MY STOMACH/ EK KRY 'N BEANGSDE GEVOEL SOOS "SKOENLAPPERS" IN MY MAAG.

Not at all/ Glad nie.......................... ☐
Occasionally/Somtyds........................ ☐
Quite often/Heel dikwels.................... ☐
Very often/ Baie dikwels.................... ☐

PTO/SOS

5

I GET A SORT OF FRIGHTENED FEELING AS IF SOMETHING AWFUL IS ABOUT TO HAPPEN/ EK FRY 'N BEANGSDE GEVOEL ASOF IETS VREESLIK GAAN GEBEUR

Very definitely and quite badly/ Baie beslis en baie erg................................ [ ]
Yes, but not too badly / Ja, maar nie te erg nie.. [ ]
A little but doesn't worry me/ 'n Bietjie maar dit pla my nie...................... [ ]
Not at all/ Glad nie....................... [ ]

6

I HAVE LOST INTEREST IN MY APPEARANCE/ EK HET BELANGSTELLING IN MY VOORKOMS VERLOOR

Definitely/ Beslis.............................. [ ]
I don't care as I should/ Ek gee nie soveel om as wat ek hoort nie.................[ ]
I may not take quite as much care/ Ek gee miskien nie genoeg om nie....... [ ]
I take as much care as ever/ Ek gee net soveel om soos altyd.............. [ ]

7

I CAN LAUGH AND SEE THE FUNNY SIDE OF THINGS/ EK KAN LAG EN DIE SNAAKSE KANT VAN DINGE SIEN

As much as I always could/ Soveel soos ek altyd kon................................ [ ]
Not quite as much now/ Nie heeltemal soveel nou nie........................... [ ]
Definitely not so much now/ Beslis nie nou so baie nie........................... [ ]
Not at all/ Glad nie...................... [ ]

8

I FEEL RESTLESS AS IF I HAVE TO BE ON THE MOVE/ EK VOEL RUSTELOOS ASOF EK AAN DIE GANG MOET BLY

Very much indeed/ Beslis baie........... [ ]
Quite a lot/ Taamlik baie................. [ ]
Not very much/ Nie baie nie............. [ ]
Not at all/ Glad nie........................ [ ]

9

WORRYING THOUGHTS GO THROUGH MY MIND/ KWELLENDE GEDAGTES GAAN DEUR MY KOP

A great deal of the time/ 'n Groot deel van die tyd...................................... [ ]
A lot of times/ Dikwels................ [ ]
From time to time but not too often/ Van tyd tot tyd, maar nie so dikwels nie... [ ]
Not at all/ Glad nie.................... [ ]

10

I LOOK FORWARD WITH ENJOYMENT TO THINGS/ EK SIEN MET PLESIER UIT NA DINGE

As much as I ever did/ Soveel soos altyd.. [ ]
Rather less than I used to/ Minder as gewoonlik.................................... [ ]
Definitely less than I used to/ Beslis minder as gewoonlik.................................. [ ]
Hardly at all/ Byna nie....................... [ ]

11

I FEEL CHEERFUL/ EK VOEL OPGEWEK

Not at all/ Glad nie..................... [ ]
Not often/ Nie dikwels nie........... [ ]
Sometimes/ Somtyds................. [ ]
Most of the time/ Meeste van die tyd.. [ ]

12

I GET A SUDDEN FEELING OF PANIC/ EK VOEL SKIELIK PANIEKERIG.

Very often/ Beslis baie dikwels.............. [ ]
Quite often/ Heel dikwels..................... [ ]
Not very often/ Nie baie dikwels nie......... [ ]
Not at all/ Glad nie............................ [ ]

13

I CAN SIT AT EASE AND FEEL RELAXED/ EK KAN AGTEROOR SIT EN ONTSPANNE VOEL

Definitely/ Beslis....................... [ ]
Usually/ Gewoonlik..................... [ ]
Not often/ Nie dikwels nie............. [ ]
Not at all/ Glad nie..................... [ ]

14

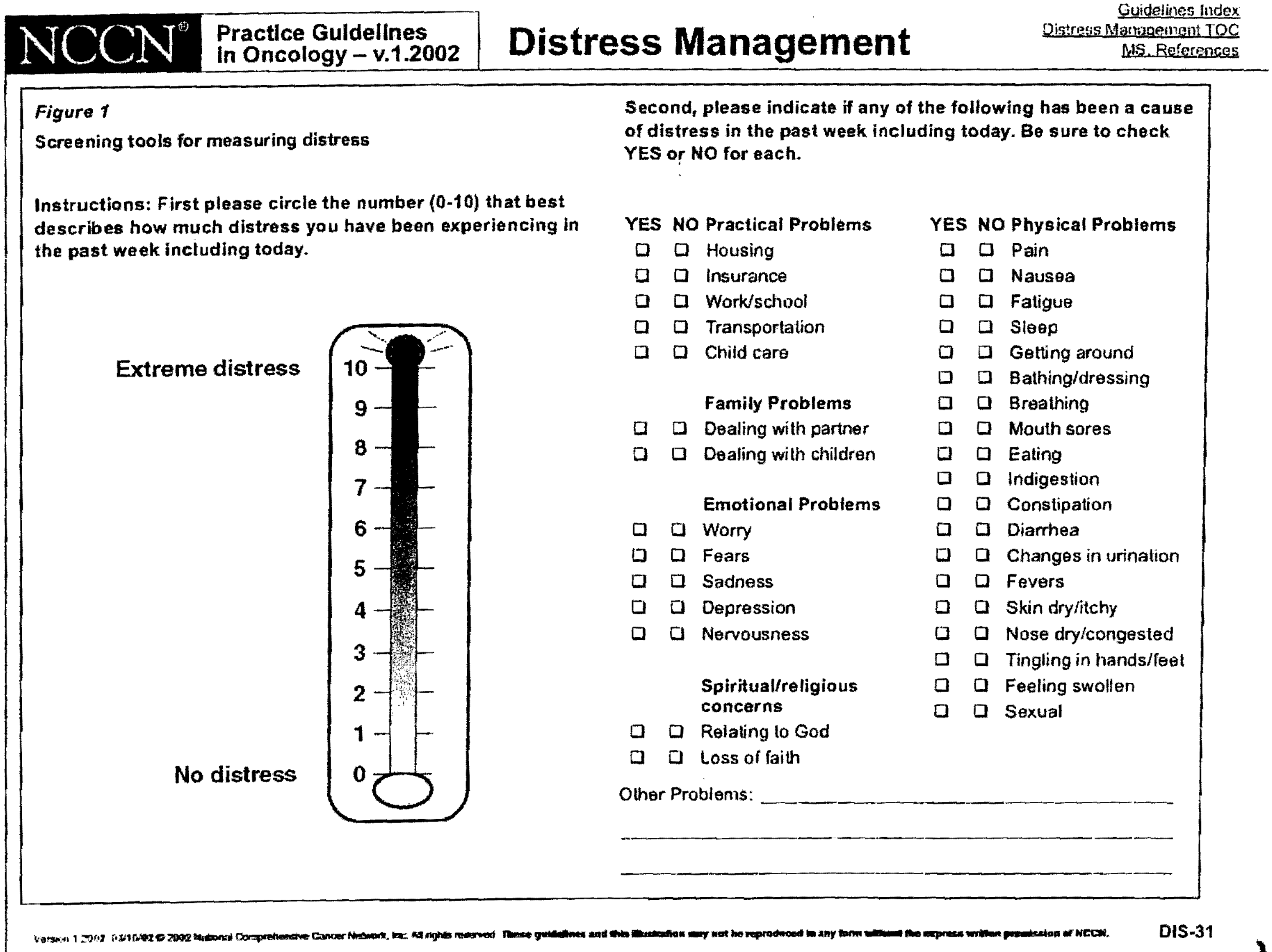
I CAN ENJOY A GOOD BOOK, RADIO OR TV PROGRAMME/ EK KAN 'N GOEIE BOEK, RADIO OF TV PROGRAM GENIET

Often/Dikwels............................... [ ]
Sometimes/ Somtyds....................... [ ]
Not often/ Nie dikwels nie................. [ ]
Very seldom/ Baie selde.................... [ ]

BYLAAG I:

VISUAL ANALOG SCALE: DISTRESS MANAGEMENT

Visual Analog Scale



NCCN Practice Guidelines in Oncology – v.1.2002

Distress Management

Guidelines Index
Distress Management TOC
MS, References

Figure 1

Screening tools for measuring distress

Instructions: First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

Second, please indicate if any of the following has been a cause of distress in the past week including today. Be sure to check YES or NO for each.

YES	NO	Practical Problems
☐	☐	Housing
☐	☐	Insurance
☐	☐	Work/school
☐	☐	Transportation
☐	☐	Child care
		Family Problems
☐	☐	Dealing with partner
☐	☐	Dealing with children
		Emotional Problems
☐	☐	Worry
☐	☐	Fears
☐	☐	Sadness
☐	☐	Depression
☐	☐	Nervousness
		Spiritual/religious concerns
☐	☐	Relating to God
☐	☐	Loss of faith

YES	NO	Physical Problems
☐	☐	Pain
☐	☐	Nausea
☐	☐	Fatigue
☐	☐	Sleep
☐	☐	Getting around
☐	☐	Bathing/dressing
☐	☐	Breathing
☐	☐	Mouth sores
☐	☐	Eating
☐	☐	Indigestion
☐	☐	Constipation
☐	☐	Diarrhea
☐	☐	Changes in urination
☐	☐	Fevers
☐	☐	Skin dry/itchy
☐	☐	Nose dry/congested
☐	☐	Tingling in hands/feet
☐	☐	Feeling swollen
☐	☐	Sexual

Other Problems: ______________________________

____

____

BYLAAG J:

VERSLAG INSAKE BYWONING VAN AOSW-KONGRES EN BESOEK AAN DIE EMORY UNIVERSITEIT.

VERSLAG INSAKE BYWONING VAN ASOW - KONGRES EN BESOEK AAN DIE EMORY UNIVERSITEIT.

TYDPERK: 2 MEI - 11 MEI 2002

(VERSLAG OPGESTEL DEUR HANNETJIE OPPERMAN - MAATSKAPLIKE WERKER, DR'S ALBERTS, BOUWER, JORDAAN EN MARE.)

VERSLAG INSAKE BYWONING VAN KONGRES EN BESOEK AAN DIE EMORY UNIVERSITEIT IN ATLANTA, GEORGIA (Opgestel deur Hannetjie Opperman)

Graag maak ek van hierdie geleentheid gebruik om my dank aan die borge en my werkgewers (drs. Alberts, Bouwer, Jordaan en Mare) oor te dra. Sonder julle finansiële insette, leiding en ondersteuning sou hierdie besoek en bywoning van die kongres nie moontlik gewees het nie. Nogmaals baie dankie.

Dankie aan "Association of Oncology Social Workers" (AOSW) wat my as gaspreker genooi het. My praatjie het gehandel oor "Post Traumatiese Stres Sindroom onder BMT pasiënte". Positiewe terugvoering is ontvang na my praatjie. Ek is ook aangewys as die Internasionale wenner van die kongres-studiebeurs vir die jaar 2002. Dit is aan my toegeken op gronde van my betrokkenheid by die stig van die Suid-Afrikaanse Maatskaplike Werk Forum, my internasionale artikels wat ek geskryf in die AOSW se tydskrif en my betrokkenheid by die voortdurende opleiding van onkologie maatskaplike werkers in Suid-Afrika. (Aangeheg, bylaag 1)

(1) Die ASOW- kongres

Op 'n sopnat Vrydag-oggend, 3 Mei 2002 land ek in Atlanta na 'n ongeveer 19 uur vlug. Op Saterdag, 4 Mei 2002 begin die kongres. Ek is opgewonde om maatskaplike werkers wat ek verlede jaar in Cleveland, Ohio ontmoet het en word ek op eg Amerikaanse wyse verwelkom, dit is met 'n "Starbuck"- koffie.

Die volgende dae woon ek verskeie werkswinkels en lesings by. Graag maak ek 'n opsomming van die lesings en werkwinkels wat ek bygewoon het.

- Ek is gekeur om die "clinical Trails Training Program", wat opleiding van 6 ure in "clinical trails" en die evaluasie van 'n pasiënt wat oorweeg word vir 'n protokol te kan evalueer.(Aangeheg, belaag 2)
- 'n Lesing oor die optimale ondersteuning aan BMT pasiënte en hul families
- 'n Lesing oor die maatskaplike werk evaluasie van 'n BMT pasiënt voor 'n BMT.
- Die assessering van BMT pasiënte met opmerklike probleme en die hangtering van die probleme soos depressie.
- Die ondersteuningstelsels vir 'n "ALLO" BMT pasiënt in die hospitaal.
- "Maak 'n verskil in 8 minute"
- 'n Werkswinkel oor die hantering van pasiënte wat selfmoorneigings het. As 'n pasiënt kanker het verhoog sy risiko om selfmoord te pleeg of aan erge depressie te ly. Onlangse studies het aangedui dat 1:1 000 kankerpasiënte selfmoord sal pleeg. Daar word evaluasie waardighede in hierdie werkswinkel aangeleer dat sulke pasiënte vinnig te kan evalueer en met die regte spanlede in te span.
- "Swaarmoedigheid en depressie". Ongeveer 20 - 25% van kanker pasiënte ly aan depressie. Simptome, evaluasies, psigo-sosiale aspekte en medikasie word bespreek.
- Assessering van BMT pasiënte met die hulp van 'n "pre and post checklist".
- Supervisie in 'n palliatiewe eenheid opset.

- Opleiding en gebruik van die "Distress Thermometer" in die hantering van kankerpasiënte en hul gesiine.
- "Quiality of life: old term, new meaning"
- Die rol van die maatskaplike werker in die hantering van pyn by 'n kankerpasiënt.
- Evaluasie van 'n pasiënt in 'n buitepasiënt opset.
- Uitbranding en die hantering van uitbranding onder spanlede.
- Simptome, gespannendheid, gemoedstoestand en ontwikkeling van "coping profiles" vir pas gediagnoseerde kankerpasiënte.
- "Hospital Etiquette: Helping Oncology Patients Dignity during their hospital stay.
- Opleiding in die psigo-sosiale navorsingsinstrumente.
- Assessering en evaluasie deur middel van 'n familievergadering.
- Moegheid- die maatskaplike werker se rol.
- (Aangeheg Bylaag 3)

(2) Besoek aan die Maatskaplike Werk Departement by die Emory Universiteit

Woensdag, 8 Mei en Donderdag, 9 Mei 2002

In die Onkologie Maatskaplike Werk departement is daar 10 maatskaplike werkers wat in verskillende sale werk. Die sale is gespesialiseerd, in kop en nek onkologie saal en die ginokologiese. Dit is dus anderste as in ons huidige onkologie opset in Suid-Afrika. Al ons pasiënte is in een onkologie saal. Ek was bevoorreg om in die volgende sale maatskaplike werksaamhede te kon waarneem:

- Die kop en nek onkologie saal
- Die buitepasiënte radioterapie areas, wat verskillende bestralingsareas insluit. Daar is 'n bestralingsmasjien vir ginokologiese buite pasiënte, 'n buitepasiënte vir kop en nek, ens. Dit is dus uiters gespesialiseerd op elke gebied.
- Die chemoterapie buite pasiënte eenheid.
- Die hematologiese onkologie saal. Die hematologiese saal voorbereidings- en ondersteuningsgroep wat een maal per week geskied. Hierdie saal het 21 beddens. Slegs hematologiese onkologie gevalle word hier opgeneem.
- Die BMT eenheid. Ek was ook bevoorreg om die oriënteringsprogram vir BMT pt'e te kon bywoon. Dit is 'n oriënteringsprogram wat elke pt en sy familie moet bywoon. As hulle dit nie bywoon nie, word hulle nie oorgeplant nie. Dit is 'n program van ongeveer 3 ure waar die hele span betrek word en elkeen sy afdeling hanteer. Die spanlede bestaan uit die dokter, verpleepersoneel, maatskaplike werker, dieetkundige, fisioterapeut, pastorale dienste, die pt en sy versorgers.

  Hierdie eenheid het 'n bedbesetting van ongeveer 90% en het 23 beddens, soms is daar 'n waglys vir oorplantings. Alle tipe oorplantings word hier gedoen, maar veral ook leukemie en limfoom. (Aangeheg bylaag 4)

- Ek was bevoorreg om "Pre-Admissions Testing" labatorium te besoek. Hier word die toetse gedoen vir BMT-skenkers, asook MUD skenkers. Die lab hanteer ongeveer 50 ondersoeke per week.

- Die "Hemapheresis" het 8 masjiene was grootliks gebruik word vir skenkers waarvan daar geoes word of persone wat plaatjies kom skenk.

Gevolgtrekking en aanbevelings

* Na intensiewe evaluasie het ek besef dat Wilgers Onkologie nie een tree hoef terug te staan nie. Ons KAN kompenteer met die beste ter wêreld. Ons het baie minder of geen hulpbronne in die gemeenskap, maar ons lewer 'n unieke uitstekende diens. Die maatskaplike werkers van Emory was verbaas en verras dat ons met so min hulpbronne en geld tekortkominge, nog kan kompenteer met een van die beste onkologie eenhede. Ek is TROTS om by Wilgers Onkologie te werk.

* Ek het soveel inligting saam gebring wat ek in verskeie areas in die eenheid kan gebruik. Tans is ek besig om al die inligting uit te sorteer en areas van implementering te identifiseer.

* Tans is besig is om 'n BMT protokol te skryf oor die voorbereiding, opname en nasorg vir BMT pasiënt en familie.

* Ek gaan ook poog om deur middel van groepe meer pt'e en hul gesinne te bereik. Ek wil die behoefte in die saal ondersoek of daar 'n behoefte is dat daar 1 X maal per week vir die lanblywende pt'e en hul familie 'n ondersteuningsgroep gehou kan word.

* Ek sal ook 'n voorlegging wil voorlê by die doktersvergadering in Junie 2002. Hierdie voorlegging gaan oor dat pasiënte bemagtig kan word deur middel van 'n "Self-care" leêr waarin daar verskillende afdelings is waaroor pasiënte inligting kan kry. Byvoorbeeld 'n afdeling vir "Hope & Cope", 'n afdeling van monitor van die pt se emosionele toestand.

* In Julie het ons 'n opleidings-middag geskeduleer, waar onkologie maatskaplike werkers in Gauteng bymekaar gaan kom en sodoende kan ek hul dan oplei in wat ek daar geleer het.

Nogmaals baie dankie vir die geleentheid.

Vriendelike groete,

HANNETJIE OPPERMAN
(Maatskaplike Werker- Drs. Alberts, Bouwer, jordaan en Mare)

BYLAAG 1

Association of Oncology Social Work
Annual Meeting May 3, 2002
Atlanta, Georgia USA

Region V Report

Region V, the international region of AOSW, currently consists of 34 members in 9 countries. Australia (8), Canada (14), Hong Kong (4), Ireland (1), Japan (1), New Zealand (1), Slovenia (1), South Africa (3), United Kingdom (1).

Thanks go out to members Ivan Hochberg (Australia) and Hannetjie Opperman (S. Africa). Both Ivan and Hannetjie contributed articles describing oncology social work practice in their respective countries which were printed in the newsletter as well as posted on the Region V website. All articles are archived on the website and I invite all members to visit the site and review the articles. I look forward to future articles from the Region members.

The Australian Exchange program continues and has expanded to include members Sydney. Ivan Hochberg and Allison Pryor continue the excellent history of the exchange. This years candidate will again attend this conference as well as Johns Hopkins and Cancer Care again this year. Our thanks to both Johns Hopkins (Jim Zabora) and Cancer Care (Carolyn Messner) for continuing to provide an enriching experience for the exchange candidates. Interested American members are encouraged to step forward for consideration of participation

The Region V conference scholarship was awarded to Hannetjie Opperman from Pretoria, South Africa. Hannetjie will be presenting information on her practice for the BMT SIG during the conference. She has also actively participated in organizing educational opportunities for oncology social workers in South Africa.

Goals for the 2002-2003 year include:
Increasing international membership
Increasing customer service to international members
Continuing contributions from region members to the newsletter and website
Continued support of the Australian-American exchange program.

Terry Baker, BSW, ACBSW
Region V Director

Missouri Cancer Associates
105 Keene St Suite 200
Columbia, MO 65201 USA
573.874.7800
terry.baker@usoncology.com

BYLAAG 2

Hannetjie Opperman

From: "Worden, Lori" <lworden@asante.org>
To: <albou@mweb.co.za>
Sent: 13 March 2002 10:06
Attach: anabnr2.gif; Nature Bkgrd.jpg
Subject: Attn:Hannetjie Apperman

Greetings! I hope I have a close approximation of your name. Apologies if I've done it wrong'

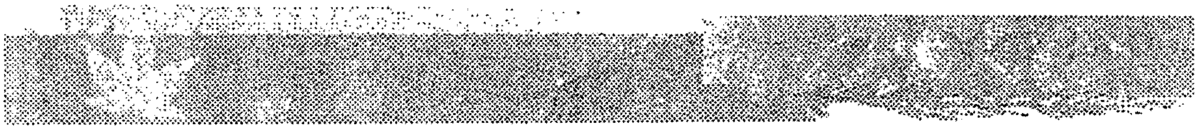
I'm writing to confirm that you have been accepted to the Cancer Clinical Trials Training Program at the Association of Oncology Social Workers conference in May in Atlanta, Georgia, US. We look forward to meeting you.

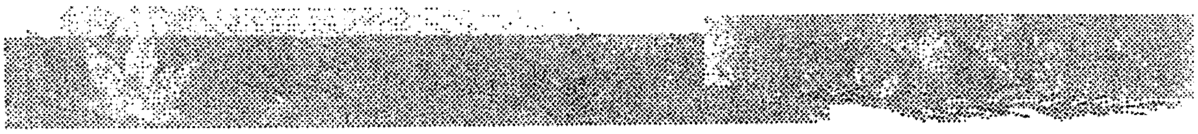
Just a reminder that the Clinical Trials Training Program does not cover any of your expenses. I know that you have applied for a scholarship to attend - I wish you success.

Please let me know if you need more information.

My best to you,

Lori Worden, MSW, LCSW
Region I Director, AOSW
Outpatient Oncology Social Worker
Spears Cancer Center
510 S.W. Ramsey Ave.
Grants Pass, OR 97527
(541) 472-7038
lworden@asante.org





BYLAAG 3

CERTIFICATE OF ATTENDANCE

PRESENTED TO

Johanna Opperman

FOR THE SUCCESSFUL COMPLETION

OF 21 CONTACT HOURS,

INCLUDING 0 HOURS IN ETHICS EDUCATION

AT THE 18TH ANNUAL CONFERENCE

Association of Oncology Social Work

EXPLORING THE DREAM

May 4 - 7, 2002

Atlanta, Georgia

APPROVALS GIVEN BY:
CALIFORNIA BOARD OF BEHAVIORAL SCIENCES, PROVIDER # PCE 946
FLORIDA SOCIETY OF ONCOLOGY SOCIAL WORKERS, # BAP 197
NASW, GEORGIA CHAPTER
UNIVERSITY OF PITTSBURGH SCHOOL OF SOCIAL WORK

Lynn Behar
LYNN BEHAR, PHD, LICSW
2002 CONFERENCE CHAIR

Judy Knapp
JUDY KNAPP, PHD, LCSW
CEU COORDINATOR

BYLAAG 4

CONTACT US...
at 404-778-7777
or 800-75-Emory
or click here for Email

GLOSSARY | SEARCH

EVENTS | CLINICAL TRIALS | FACILITIES | HEALTH TOOLS | MY RECORDS |

FIND A PHYSICIAN
INFO FOR PATIENTS
CONDITIONS & CONCERNS
DEPARTMENTS & SERVICES

Bone Marrow Transplant
(BMT)

The Emory Bone Marrow and Stem Cell Transplant Center

As one of the world's leaders in bone marrow and stem cell transplants, we are committed to the latest, innovative techniques and treatments with supportive services and compassionate patient care.

Our mission is to provide curative therapy for patients with cancer using combinations of high dose chemotherapy with bone marrow or blood stem cell transplants.

Our participation in national, international and institutional clinical trialsassures that we offer patients the newest knowledge in stem cell biology and transplant immunology.

The Emory BMT staff of experienced, progressive physicians, nurse practitioners, nurses, pharmacists, social workers, dieticians, physical therapists and clergy work as a multidisciplinary team dedicated to comprehensive patient care.

Please refer to the menu at the right for complete information and services for the Emory Bone Marrow Transplant Center.

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