

THE HAEMOPHILIA SOCIETY

VISIONING WEEKEND FOR PARTNERS OF REGISTRANTS WITH HAEMOPHILIA AND HIV

9TH -10TH JUNE 2001

organised by Babs Evans, HIV/HVC worker

**DESCRIPTION OF THE PROCESS (with appendices showing
causes and consequences of stress for the primary carers; and visions
and strategies suggested by them)**

Alice Welbourn, Facilitator

PARTICIPANTS

There were 3 participants, all women, from different parts of the country. This number was fewer than the 10 planned, but there were a few last minute cancellations. However, it was decided to continue with the weekend nonetheless. Complementary therapy sessions were available for all participants and for the facilitator.

INTRODUCTIONS

NAME GAME

The work began with a name game. Each participant and the facilitator wrote down her name, together with an adjective to go in front of it. As she wrote it, each person described something about her name and the adjective she had chosen, such as what she thought of her name, or why it had been given to her, and why she chose that adjective.

GROUND RULES

The facilitator then established the ground rules for the group. Below appears what were suggested, discussed where necessary and agreed. These were listed on a flip chart and posted on the wall.

Confidentiality
Honesty
Time for people to talk
Respect for others' points of view
Keep some music playing quietly
Smoke outside the room
Say what we don't like doing at the time

HOPES/EXPECTATIONS

That we get to know each other better
That this is on-going and doesn't stop here
That we can be honest
That we have a laugh
That this is positive for the future
That I feel comfortable crying
(Facilitator) I hope you feel the day is worthwhile
(Facilitator) with the smaller group I hope there is more time for sharing

FEARS

That nothing will happen from today

That I will cry and be upset
That it will be pointless
That I will be judged
That I will feel guilt
(Facilitator) that this is the first time I have worked around these particular issues
(Facilitator) that there is a smaller group than I am used to working with

Both these lists were written up on a flip chart and posted to the wall, ready for review on Sunday.

AGENDA

The facilitator presented the proposed agenda for the day, explaining that this could be changed if the participants preferred. However this agenda was accepted by the group.

Planned agenda

Saturday

12.00 Visions
1.20 Lunch
2.20 Looking at issues
3.30 Tea break
4.15 Planning for the future
6.00 Close

Sunday

9.45 Evaluation

In the event, the Saturday session ran on until 7.20 and two exercises which the facilitator had hoped to cover in that last session were left for the AGM on 24th June. On Sunday am participants worked more on planning for the future, as well as the evaluation.

VISIONING EXERCISE

GUIDED VISUALISATION

This began with a guided visualisation exercise which lasted for about 10 minutes. The facilitator asked participants to lie flat on their backs, with pillows under their heads. She then guided them through an established meditation exercise, designed to increase creative energy flows, whilst music played quietly.

WISHES

The next stage of this process involved participants writing ideas of post-it stickers. Before the weekend the facilitator sent the participants an introductory letter, asking each of them to think about their lives and to write a list of 5 things which they would like to see changed in a perfect world in, say, 5 years' time. They were asked to bring this list with them to the workshop. The facilitator now asked the participants at the

workshop to write up each of these ideas on a separate post-it, encouraging them to add more wishes if they would like.

As the participants wrote out the post-its, the facilitator stuck together several sheets of flipchart paper to make a large tree. One of the participants drew the tree on the sheets and then all participants stuck their post-its on the branches of the tree.

The participants then all had time to read all the wishes, to comment on them, and to question and discuss any which they weren't quite clear about.

I'm amazed how similar all our wishes are. On the way here I was making up my wishes and I thought – oh no-one will have my wishes, I'm sure they are wanting something else from me, not this. But now I've seen that our wishes are all the same.

The facilitator then asked the participants to group their wishes according to similarity of issues, along the branches of the tree. Ten branches emerged, one for each issue, grouped by the participants' according to their own wishes. Next the facilitator asked the participants to give a short name to each branch which would, in some way, summarise the post-its hanging on that branch.

This went on later than planned, as the participants became engaged in discussing the issues which had emerged. However eventually one participant went off for a pre-arranged complementary therapy session while the others broke for lunch.

LUNCH

LOOKING AT SOME ISSUES

WARM-UP GAME

The afternoon session began with a game with lively movement and music – called frogs and lily pads. It is another version of musical chairs, with old pieces of newspapers for lily pads. It works very well with a large group but – perhaps expectably – worked much less well with such a small group. It still caused a bit of laughter, however, which was important since this next session, as the facilitator explained, was going to be quite tough for the participants. She explained further that she felt it important however to explore some of the challenges facing them, in order then to move on to thinking about ways in which some of them may be overcome.

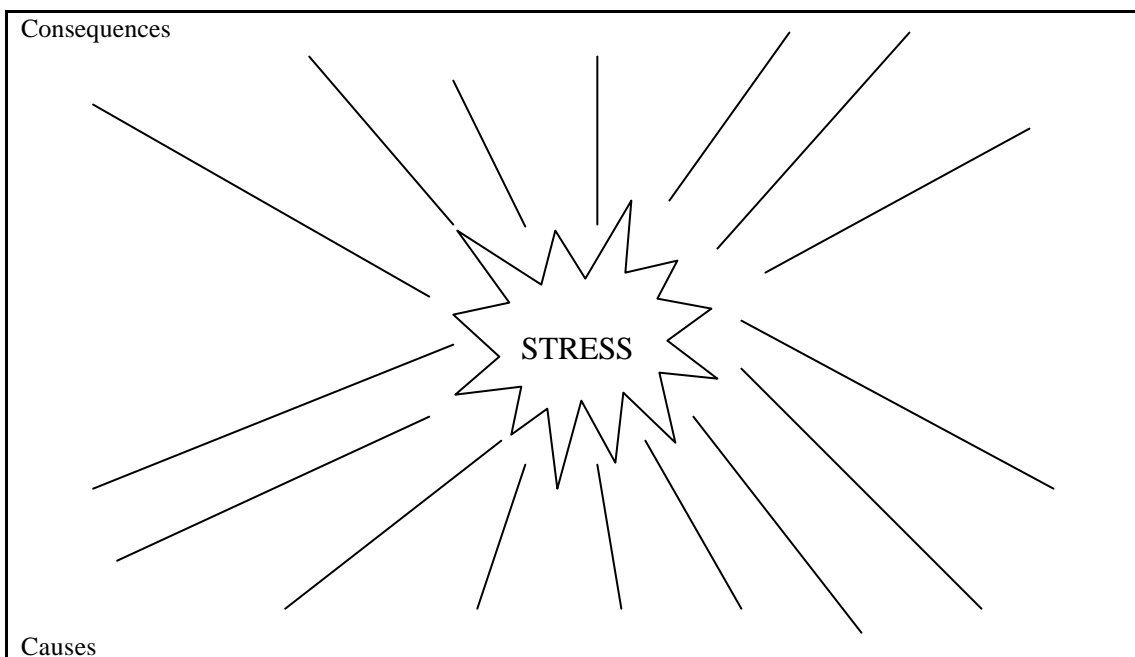
STRESS CHART

The facilitator stuck two pieces of flipchart together and wrote “stress” in big letters in the centre. She asked participants first to think of all of the causes of stress in their lives, no matter from what source, irrespective of whether they related specifically to their partners' medical condition or not. Each cause was to be written on a separate post-it sticker. Participants then stuck all of these on one side of the large sheet.

Once they had finished sticking them, the facilitator again asked them to discuss any which they thought unclear and then to group them as they saw fit into similar subject areas, developing a star burst image of post-its, radiating out along different subject lines, from the central word.

I realise again that there are similarities in what we have written. I've always thought I'm the only person thinking these things, but now I've realised that I'm not alone. In fact you've also written some things which remind me of other things I want to add to this.

The same process was then followed for the consequences. This process produced similar reactions. (See Appendix 1 for table of causes and consequences of stress.)



Once more this exercise took more time than was really available on the day. The facilitator pointed out the time problem to the participants. However this was initially rejected, because the participants really wanted to discuss and share many of the similarities which were emerging for them in their experiences. Finally, however, they agreed that they felt ready to move on from this exercise.

CLOSURE

In order to draw a line under this section of the day, the participants and facilitator stood in a circle with their hands placed over each other in the centre. Then on the count of 1,2,3, they threw their hands out and up into the air above them, whilst calling "whoosh". This was a symbolic way of bidding farewell to these stressful thoughts and moving on.

TEA BREAK During this break another participant had a complementary therapy session.

MARGOLIS WHEEL

This is an exercise where each participant takes the opportunity to air a real problem and have one-to-one advice from other participants in turn. In large groups it works extremely well and is normally found to be a very empowering exercise, helping people to realise that we all have problems and that through sharing them in this way, we can both receive and be the valued givers of good advice. On this occasion however, it didn't work well, largely because there were too few people and partly because, in order to try to make it work, the facilitator had encouraged participants and the HS worker to do the exercise together. On reflection this was unfair all round, because the HS worker did not otherwise take part in the workshop, and so broke the sense of continuity. On reflection, it would have been much better for the 3 participants to take it in turns for 2 to give advice to the third for equal amounts of time.

PLANNING FOR THE FUTURE

The final session for the day began with a discussion of time frames and participants agreed to work until about 7pm. All the exercises for this session referred back to the tree which had been drawn earlier.

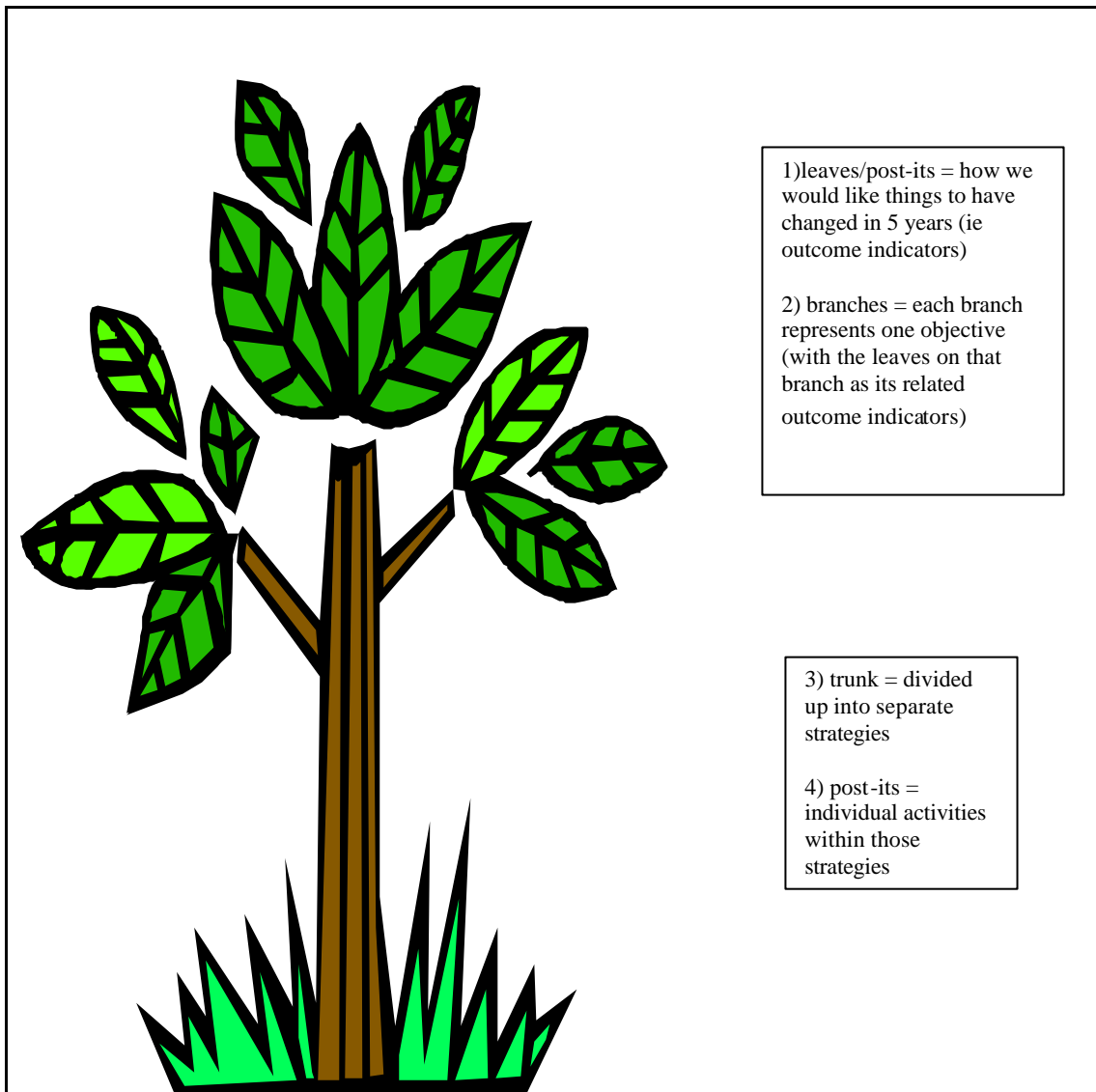
The facilitator began by explaining a bit about her plans for the rest of the session and about strategic planning processes. She explained how each branch of the tree could be related to a different objective, and how the session would first address the wording of these objectives. She then explained how she would next ask participants to brainstorm on strategies – on ways in which the participants felt their objectives could be achieved. These strategies would be stuck on the trunk of the tree. She then explained how later on the roots of the tree, if they wished, could be viewed as activities; and how the wishes which participants had stuck on the branches initially could be viewed as indicators to measure the extent to which they felt their objectives were being achieved over time.

DEFINING OBJECTIVES

The facilitator asked the participants to take another look at each branch of the tree, to which the participants had earlier assigned a word or phrase. There were 10 branches, so each participant took three branches. With each branch, participants were asked to develop a statement of objective, starting with “to....”. The idea was to produce a statement which would be positive and which would reflect where the participants would like to *be*, or to *have* in the future. Once the participants had each had a go at their own three statements (and a tenth statement for the last branch had also been created), everyone looked together at each statement in turn, to see if there were ways in which the objective could be developed or improved. So for instance, one statement which read “to struggle to get....” was changed to read “to *have*....”.

Once the participants were happy with all the objectives they had created, the facilitator asked them to brainstorm on activities which they thought might help to achieve these objectives. Participants wrote these on individual post-its and attached them to the trunk of the tree. The trunk was soon covered with a mass of stickers as more and more ideas flooded out. It also helped to refer back to the stress chart. By checking round the stickers on the “consequences” side of the chart, participants

thought of extra activities to add to the trunk, which might help to address some of the consequences of stress which they currently experience.



THE VISION TREE

I found this session and the stress diagram really therapeutic –getting it all out of me from here (she pointed to the pit of her stomach)

The ideas kept flowing, but finally at 7.20 it was time to stop, so that the third participant and the facilitator could have their therapy sessions before supper.

See Appendix Two for a table of visions and suggested strategies.

CLOSURE

The day was brought to a close by each participant stating one thing that she had learnt and one thing that she had not liked. There was general consensus that

participants had not found the Margolis Wheel easy. However they did say that they had learnt that they were not alone in what they were experiencing in their lives.

SUPPER

In the evening, the participants, the facilitator and the HS officer all had supper together and discussions continued – for those with better staying power! – into the small hours.

SUNDAY

After Sunday morning breakfast together at 9am, participants, the facilitator and the HS officer met to decide what to do next. This involved discussions on how to write up the workshop, who to send the report to, how to take the findings forward to the AGM and other meetings, and so on.

FURTHER WORK ON THE DIAGRAMS

Participants anonymised all the stickers on the tree and stress diagrams, in order that they could be written up and also made available for public viewing. Participants also grouped all the activities which they had stuck to the tree trunk into similar issues, to create separate clusters of activities, as strategies. Some activities appeared as part of more than one strategy.

The facilitator then talked through with the participants and the HS officer two further exercises which might help the participants to start to prioritise strategies. These might be conducted during the AGM meeting on 24th June. The HS officer then left the room. Ways in which other partners and carers could be included, both in this process and in future events, were discussed.

I think it's really important for other carers to do these kinds of exercises for themselves, because it's so therapeutic and then they can come up with their own ideas for themselves

The participants also decided to develop the group into one for other carers, not just partners, and for carers of registrants with HVC, not just HIV. One suggestion for the group's name was the OAC group, reflecting the strong OAK tree which they had drawn: and standing for "Organic Action by Carers".

EVALUATION

Finally it was time for evaluation. The facilitator wrote up a flipchart while participants tore up some paper to make little balls for marking.

Criteria for evaluation were suggested partly by the facilitator and partly by participants.

The facilitator then left the room while participants marked their scores on the chart. Participants also wrote their comments about the weekend on the “graffiti board” – another flipchart.

The participants filled these in as follows:

<i>Criteria:</i>	😊 😊	😊	50/50	😞	😞 😞
Drawings and methods	3				
Support from HS Officer	3				
Humour/seriousness balance	3				
Therapy	2	1			
Length of day		3			
Results from weekend	3				
General style of facilitator	3				
Hotel in general	2	1			
Meeting room					3
Sharing experience	3				

When they were ready the facilitator came back in for a very brief discussion of the results, (the facilitator had a train to catch) and thank yous to the HS Officer, the therapist and the partner who had arranged the booking at the hotel, before a final - and loudest - “whoosh” closing exercise.

Overpage appears the “graffiti board”.

Graffiti Board

While it was very emotional, I still found it a productive experience

It created a lot of positive energy

I would like to use these drawing exercises in my own work

I am feeling empowered by the experience

It was an unusual and positive way of pulling feelings out

I am feeling emotionally exhilarated – and exhausted too

I feel excited about the development of the group and the future

We've got to share this with other carers and parents

(for other comments from participants, please see the text above)

What else to do.

- Objectives: at some stage, especially if you were wanting to develop a funding proposal, you would need to work further on these. Objectives nowadays are expected to be SMART (specific, measurable, attainable, realistic and time-bound). Remember though that measurable can be qualitative and not just quantitative measurement – think of the smiley faces evaluation chart you used.)
- Then think about your indicators. These were the very first post-its you put down, which will help you to assess how well your objectives are being achieved: it is also a good idea to try to make these indicators both SMART and SPICED: Subjective, Participatory, Interpreted and communicable, Cross-checked and compared, Empowering and Diverse/disaggregated. I will go through what each of these means in turn:
 Subjective: ie based on your own specific knowledge and expertise of the situation you are facing
 Participatory: ie developed by you!
 Interpreted: this may mean that others reading your post-its at present may not quite understand what you are getting at, so they may need some further explanation for others to understand what you mean by them
 Cross-checked: eg by using different group members, service providers, etc.
 Empowering: the process of establishing these indicators should feel empowering to you, and enable you to go on reflect on your changing situation as you use them to assess that
 Diverse: this means seeking out different indicators from a range of different people, and recording them in such a way so as to keep track of who has said what, so that these differences can be assessed over time. I will come back to this below, under WHO...

- Developing your strategies into activities. Once you have done the implementation/impact exercise and the what/who/when/how exercise, you will then be ready to develop the strategies further into specific activities. At this stage it may well be a good idea to do other exercises which explore further your needs in particular areas, such as legal support, emotional support etc. There are other drawing exercises which could help you to explore these issues, some of which might be quite tough to do, but which might help you to develop a clearer understanding of what specific activities might help you to address them. I could give you some ideas on appropriate exercises, if you would like them.

Strategy Matrix:	Low impact	Medium impact	High impact
Low effort			
Medium effort			
High effort			

What	Who	When	How	Where

- Then WHO. I think it's great that you are expanding the group to include carers and also carers of people with HCV co-infection. I think it would be good though for you also not to lose sight of your own particular needs within this larger group. In the group, I suppose you might have smaller sub-groups of, for instance...
 - * gay men; * HIV positive women; *HIV positive gay men; * straight men who are primary carers (eg brother, father, friend..); *carers whose partners or sons have died; * younger carers * and so on

People may fit into more than one sub-group and feel happier in one or another. Others may not wish to identify with any particular sub-group: and sub-groups might change over time. I would like to suggest that you encourage each sub-group that identifies itself to do the same exercises as you for themselves, so that they go through the same learning process for themselves as well as developing a forest of cross-fertilising oak trees! The important thing here is to validate everyone's difference of experience and learn from each other not only about what you have all in common, but also to respect what differences you have. This will help to build your strength of unity and identity as a group whilst respecting also your diversity. I suggest this because outsiders so often assume that people with HIV, for instance, all have the same needs. So if you manage to respect and embrace that diversity of perspective from the outset, I hope it will make you stronger as a group.

- Then of course, as we talked about, it would be really great if eg the Birchgrove group were interested in a similar exercise – and HS staff, trustees, MFT ditto – and then what about some service providers at HCs around the country... etc., to build up a comprehensive picture of who thinks what and how your perspectives overlap... and differ!

I hope this doesn't all sound to daunting. I've got various things to read on all this if you would like...

Also, I think I mentioned to one of you, I know of a man who started up a group for partners of people with breast cancer. If any of you likes, I could find out a contact for him, if you would ever be interested in having a chat with him.

APPENDIX ONE: Stress – causes and Consequences

STRESS

Causes

1	2	3	4	5
Treatment strike	Difficult people in my life	Professionals	Other expectations of what partner can do	Washing dishes
Watching partners suffer mentally and physically	Other people's expectations of me	Professionals	Widowed mum	Cooking and housework
Partners physical and mobility problems	People moaning about little things	Civil servants	In-laws	Living in cold, cold Britain
Worries about coping with partners illness	People thinking I'm strong	Friends saying why didn't you come to me	Family expectations	Not being able to live abroad because of HIV
Being second to illness	Arrogant people	Tony Blair	Family pressure	
Partners giving up	Ignorant people	MFT	Children	
Future	People saying I understand	Being disregarded		
	Incompetence			
	Being disregarded			
	Lack of support from friends			
	Friends saying I am here when if you went they would run a mile			
	Making new friends			
	Isolation			
6	7	8	9	10

Work	Worries about death and dying	Telling lies	Dog	Lack of security re: home if partner dies
Work – not enough time in the day	Worries about being left alone	Being secretive in your own home	3 cats who make a mess	Lack of money
Studying		Hiding office documents for fear of being found out		No money
				No pension
				Lack of life assurance

Consequences

1	2	3	4	5
Can't make plans	Low self-esteem	Makes me depressed	Lack of communication with partner	Under achieved
	Low self-esteem	Depression	Have problems with relationships	Careers on hold
	Weight gain	Liar	Lack of sex drive	Resentful
	Started smoking again	Cold weather makes partners joints ache – feel helpless	Don't know who my real friends are	
6	7	8	9	10
Spend far too long cooking and cleaning	Eat too much	Short tempered	Illness/never feeling 100%	Overdrawn
Run around after people all the time	Lonely	No patience	Own health worries	Benefit trap
	Feel lonely	Fretful		
	Isolation	Bitterness towards others		
	Feeling guilty	Makes me bad		

		tempered		
	Scared	Nobody understands me		

APPENDIX TWO: VISIONS TREE AND STRATEGIES

The Oak Tree

The main suggestions I would make to the group is that they add some kind of key beside the tree perhaps to make it clear what is an objective, what are the original wishes which are indicators of reaching that objective, and what are the strategies. The words you've put in bold were just quick phrases to label each branch, before objectives were created. One or two of them no longer make direct sense now the objectives have been developed. They may want to reword them – or drop them all?

Branches

Family	Support for carers	Health	Public recognition as carer	No stigma
Obj: To be able to work without financial penalty and have flexibility for when partner is ill	Obj: To feel listened to and supported as a carer	Obj: To ensure continued good health and quality of treatment	Obj: To have the choice of a family	Obj: To change public attitudes
Indicators: Flexible job (partners health)	Indicators: No blame on me as a carer	Indicators: Recombinant Factor VIII	Indicator: To adopt a child	Indicators: To be open about status
To be a successful full-time complementary therapist	No judgements but lots of support	Cure		To be able to talk freely i.e. cancer
Full-time job		To be in personal good health		
To get married		Good health		
Independent		To find a cure		
To be open about relationship				
Recognition as individual from HS and MFT	<i>Financial security</i>	Escapism- own space	<i>Sex</i>	<i>Information</i>
To be recognised as independent individual with specific needs as a	Obj: For the government to admit responsibility and provide adequate	Obj: A respite home in the sun	Obj: To have worry free sex	Obj: To receive regular up to date and honest information

result – <u>affected</u> by illness	compensation			
	Indicators: Full-time job	Indicators: A separate residence home and abroad	Indicator: Unprotected sex	Indicators: Well-informed with up to date information
	<i>Compensation Hep C/CJD</i>	To live for 6 months of year abroad		
	To be financially independent from MFT	Living on our own		
	To be financially secure			

The trunk (strategies)

<i>Knot 1</i>	<i>Knot 2</i>	<i>Knot 3</i>	<i>Knot 5</i>	<i>Knot 4</i>
Partners/carers representation at AGM	MFT recognises carers as having rights	Funding for partners/carers group	Research	Training to deal with professionals
Explore strategies to contact/support new partners/carers	MFT/HS to adopt inclusive practice	MFT to fund significant others after partners' death at same rate as partner as no life assurance	Funding for anonymous blood tests	Training for service providers to be non-judgemental
For HS to communicate with local authority regarding benefits to avoid harassment	MFT regarding registrants having rights not needs	MFT/HS to purchase a house in the sun and fund registrants and partners to visit regularly	Funding	
To ascertain why partners did not attend event	More welcoming approach from HS, especially on the phone	A monthly carers grant from MFT (not linked to DSS)	MFT to fund complementary therapies unrestricted	
For partners to commit to stay in touch and move on	To be strong enough to talk	MFT to address shortfall in income if carer works	MFT to fund IVF or adoption	
Website for carers	Helpline	A clear criteria for funding applications and to stick	Explore counselling service/funding	

		to it		
Partners group representative at Partnership group	For MFT and HS to listen to and action and to respond to these comments – feedback please by 3 months after event			
For more partners/carers to get involved to create a group	Partner/carers support worker	<i>Knot 6</i>	<i>Knot 7</i>	<i>Knot 8</i>
HS to explore how to reach new partners		Public enquiry	Access to legal advice	Increased positive media attention
For partners/carers to have a voice i.e. regular meetings				