



The effect of MS on the family and relationships

Chatroom

20 September 2006

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20 September 2006 – 10am to 7pm

- **Kerry Mutch** – MS specialist nurse (10am – 2.30pm)
- **Julia Segal** – MS specialist counsellor (10am – 3pm)
- **Jane Ware** – MS specialist nurse (3pm – 7pm)
- **Kate Watkiss** – MS specialist nurse (3pm – 7pm)

This chatroom is an open forum and so the views expressed by participants are not necessarily those of the MS Trust. For further information on topics raised, please contact the Information Team at infoteam@mstrust.org.uk

Books by contributors referred to in the chatroom:

- Kerry Mutch. The Young Person's Guide To MS. Letchworth:MS Trust;2006. ISBN 1904156096
- Julia Segal. Helping Children with Ill or Disabled Parents: A Guide for Parents and Professionals. London;Jessica Kingsley Publishers:1996. ISBN 1853024090

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Simon - MS Trust: Welcome to the chatroom. Does anyone have a question for Julia or Kerry?

Rohan: Have you any tips or strategies as to how people with MS can better communicate their feelings to family/friends and vice-versa?

Kerry - MS nurse: The best tip is not to keep all your feelings bottled up. Speak to someone you trust at a quiet time about your feelings. Most people want to help and, by talking, will help you.

Julia - MS specialist counsellor: I think it is very difficult to communicate with families. You worry about upsetting them. With children you can't always talk; you may find other ways to communicate such as playing with dolls - the doll's daddy has to go to hospital, for example, so you can find out how the child feels. Watching films together can also help open up conversations. Sometimes you can communicate with a teenager through listening to the words of the music they play.

Shaun: Once again the MS Trust has done a brilliant job with the latest publication. Effects on family can be huge, but not all are negative. My children are I feel more caring and helpful where they can be.

I have MS and work for two MS charities and although I cannot work full time, I get great satisfaction from what I do and encourage others to do this, if possible. My message is, talk to family and friends, tell them how you are feeling and let them ask you about your MS.

Geoff: My wife has MS and it takes a lot of effort not to let this become a barrier - not because she makes it so, but MS does stir up so many things.

Kerry - MS nurse: The barriers often arise because people don't want the MS to become a burden and often don't think their MS is causing any problem to anybody else, but it is the silent symptoms that cause most worry to others.

Geoff: I think that's very true. I worry about her all the time, but she seems to be coping pretty well with what MS throws at her. Sometimes I don't know whether to say something and seem smothering or stay back and fret quietly.

Julia - MS specialist counsellor: MS does stir up things for everyone. It may help if you can offload some of your anxieties to someone else - I'm a counsellor so I'm biased towards counsellors. It's not always possible to talk to family or friends. Can you tell us about the smothering and the fretting quietly you are talking about? It sounds important and I think other people may recognise it.

Kerry - MS nurse: Honesty is probably best. Get it clear between you that when she needs help/wants it she can ask. As you say you probably worry more than your wife as you can't do anything about it, whereas your wife is actually dealing with the situation.

Julia - MS specialist counsellor: You have described a very difficult problem; whether to let a person know you worry about them, or whether to keep quiet. If you let them know, you worry they may be reminded, or feel worse because you have mentioned it. If you say nothing they may not even realise you care. Honesty is easier said than done. Being honest also has to include being

considerate of the other person's feelings. It's also not always clear exactly what is the honest feeling; since feelings change once you've spoken them, but spoken words can't be unsaid.

Geoff: It's hard to find someone to talk to about worries - is that a bloke thing? :-) My friends don't really know much about MS, and are sympathetic but don't really understand - especially when it's about fatigue or dizziness or something internal like that.

Rohan: Certainly is hard, Geoff. I am very conscious that it is almost impossible for healthy family/friends to understand what it feels like to 'exist' in a body that has MS (with all its myriad of symptoms) and therefore sometimes the support may be a little wide of the mark. It may also be very difficult for the person with MS to appreciate that friends/family are also experiencing daily stresses, strains and hassles.

Kerry - MS nurse: It is a man thing and a national thing that MS often gets bad image. Only physical signs are seen and not other symptoms, such as fatigue and dizziness, that are so difficult to deal with the daily fluctuations. Maybe you could talk to a local MS nurse.

Geoff: It's a condition with so many twists. I think I'm forever worried that another nasty twist is about to appear. In a strange way, I think there's a difficulty in not being the one with MS. My wife's hardly in the driving seat, but I sometimes feel like the blindfolded passenger in the back. Not sure that makes sense.

Kerry - MS nurse: I think this is so true.

Shaun: I didn't think that I would ever need to talk to an MS Nurse, but when I did, it was so worthwhile and completely confidential and if I felt the need to again, I would.

Julia - MS specialist counsellor: Fatigue, dizziness, memory problems, concentration problems are all the awful invisible symptoms that other people may misinterpret. That anxiety about the unpredictability is a very common one. It's difficult just to get on with life and ignore it. People who live with someone who has MS can sometimes find themselves feeling as if they had some of the symptoms themselves, particularly the anxieties. I like your analogy of the blindfolded passenger in the back seat.

Kathy: In answer to Geoff, I think that women are prepared to discuss emotional issues - sometimes (not always) men don't always open up, so it is harder for men to talk through emotional problems. I think men hold back slightly more. Maybe it's still to do with society's definition of 'masculine' behaviour, which produces a bit of a barrier. It's changing now thankfully, but the current generation still have a few obstacles in the way. Men have emotional worries too which they must be allowed to express.

Julia - MS specialist counsellor: I have been interested to find that many men come to me for counselling and find it helpful, often when they didn't think they would. Our local Carer's Association also has opportunities for talking, either one-to-one or in groups. And our Community Rehabilitation Team has a counsellor, a psychotherapist and two psychologists who are all available for partners/carers as well as for the person with MS. The managers recognise that helping a partner with their anxieties can help to keep someone at home and prevent people being pushed over the edge. Women as well as men can

sometimes be pushed to the limit by the frustrations of MS, and this can be dangerous.

Geoff: The idea of talking to the nurse sounds good. I'd not even thought of that - I'd always assumed the nurse was for Helen.

Kerry - MS nurse: Our aim as nurses is to support, inform and educate all people affected by MS, although partners are often forgotten. Newly diagnosed courses and other courses are usually run for both partner and the person with MS. This was a main reason for my workshops MS in the family aimed at 9 -15 year olds who have parents with MS to explain MS further and let them talk.
[for more on these courses, see Open Door, March 2004 – available from the MS Trust]

Julia - MS specialist counsellor: The Expert Patient Programme courses can also be also good for partners/carers as well as the person with MS (or whatever other chronic illness).

Kathy: My children have grown up and left home. I find it is important to keep them informed about any temporary difficulties you have so that they can feel involved and that they can help you and take some of the pressure off your partner, so that they don't always get the brunt of your frustration.

Julia - MS specialist counsellor: Children do generally appreciate being kept informed. Sometimes it can be difficult keeping the balance between making sure you are listening to their problems too. I'm sure you do, Kathy!

Kerry - MS nurse: Children have different needs at different ages. The younger child will cope with any physical problem – it's just Mum/Dad. But as they get older they start worrying about the effects on them.

Shaun: A question for Julia. As my children are now older, the oldest (21) has asked me if he might get MS. I know it's a small chance but I felt for some reason guilty and cold. Is this a normal feeling?

Julia - MS specialist counsellor: Ow, Shaun, it is such a horrid feeling. Yes, lots of people feel guilty and cold and terribly anxious when their children ask - as if we were responsible for our genes. The facts are: children of people with MS have about 1 in 100 chance of getting it. Several genes are involved, but also other factors such as environmental elements and possibly diet.

Shaun: Thank you.

Julia - MS specialist counsellor: I find it remarkable that people feel so responsible for the health of their children, but of course we do. I suppose we could have chosen not to have children if we had some illness, but I'm not sure they would thank us for that.

Kerry - MS nurse

Most people do not know anybody else in their immediate family unit with MS, although there are some families that appear to have a tendency towards autoimmune diseases.

Rohan: Do you feel that the promotion of group sessions for people with MS and their friends/families involving information/chat/fun/activities could benefit the long-term health of many individuals and their relationships?

Kerry - MS nurse: I think these days /sessions open doors and break barriers down within the family unit.

Julia - MS specialist counsellor: Group sessions can be very helpful for some people, but if they are badly run they can also be destructive in some circumstances. Groups are powerful and can be a force for good or bad.

Rohan: How could one go about organising a group session and what would be good subjects/topics?

Julia - MS specialist counsellor: The MS Society and other MS charities sometimes run really helpful information sessions and other activities such as you describe. These can be a great support, for those who get involved in running them as well as other participants. I'd look for your local MS charity/self-help group first. Failing that, do you have a local disability organisation? There are lots of hot topics people might come out for. I won't mention them here because I don't want to derail the focus of the chat. I run workshops about emotional reactions to MS, though I wouldn't start with that one.

Kerry - MS nurse: Many MS nurses run several different groups. Expert patient programmes are useful in promoting self empowerment.

Simon - MS Trust: The MS Society have a list of their branches on their website - www.mssociety.org.uk or ring 0208 438 0700. Therapy Centres often have drop in or support groups - www.MS-selfhelp.org / 01234 325781 or www.mstherapycentres.org.uk / 01738 840357 (Scotland).

Rohan: In truth, I feel that self-help groups can be a bit hit and miss. Would it be a good idea to pool information from successful sessions/group, and have this info available for others who wish to run meetings/sessions?

Kerry - MS nurse: The difficulty is access to the info and pooling it. The MS Trust and MS Society do a great job at trying to share info and making it nationwide.

Rohan: Thanks Kerry, I'll contact MS Trust/MS Society HQs to see if they can furnish me with some info/ideas.

Ian: Not long after my wife was diagnosed, we went to a meeting and it really freaked me out. Everyone I met wasn't a person, but a possible way my wife would end up. She found it really helpful but I couldn't go back.

Julia - MS specialist counsellor: I understand your problem. Sometimes doctors used to advise people not to get involved with MS Society meetings because of the fear they would be freaked out like that. It is so difficult, because by not going you deprive yourself of potentially very important and useful information as well as support from others who really know what it is like, even when your wife has 'invisible' MS.

Kerry - MS nurse: This sounds as though it was a local MS branch meeting where often the more disabled person is present. They may actually be the people getting on with their lives but they are the ones seen and unfortunately

add to the tension that all MS people end up in wheelchairs. Specific newly diagnosed courses are run for people diagnosed in the last year, and so hopefully aren't so scary. Please speak to your local MS nurse.

Julia - MS specialist counsellor: One of the things people sometimes use counselling for, is to sort out 'how I would cope if the worst happened. . . ?' This is helpful because it means you've faced your worst fear and you know you can handle it. Once you've done that you might be able to see the person, not just the wheelchair. But I know it can be very difficult for some people. Some people have specific reasons for fearing certain disabilities too, which can sometimes be changed in counselling.

Ian: All the people there were very friendly and my wife's made several friends, but I was quite upset by my reaction. It seemed so blinkered and made me want to put my head in the sand.

Julia - MS specialist counsellor: Don't beat yourself up about it, Ian! Many partners feel like you. We can't all be PC all the time. It may have been the first time you had really had to confront what the MS could potentially mean. The early thoughts about that are often shocking, frightening, even terrifying. It is only as they get used to them that people become more able to think about the MS with sense, including problem-solving. For example, I find it can take people two years or more to get used to anything upsetting. I don't know if this applies to seeing other people whose MS is worse than your wife's.

Ian: I think it was also a blow to my pride. When she was diagnosed, I thought my wife would need protecting and looking after, but I find she's OK with lots of things and I'm the one that's struggling.

Julia - MS specialist counsellor: I do sympathise. MS throws so many things at families, it can change the whole dynamics. People often have problems in their relationships because they expect their partner to respond as they think they would respond themselves.

Ian: That is true I fear. I don't want to sound like a caveman here, but the idea of protecting and looking after my wife was blown away by the response to the meeting. And I feel guilty that as well as worrying about what's in store, much of my reaction was about me and what I felt and completely at odds with why we were there.

Julia - MS specialist counsellor: Carers share the anxieties, the future, the losses; MS affects you too, when you would much rather be the supporter, basically unaffected. MS hurts! But you may be able to find a different way of supporting, which involves sharing and possibly acknowledging that you need your wife's support too, perhaps? Some people with MS are good at supporting their partners, others can't. MS sometimes makes people feel useless, (both people with MS and their partners). Allowing your wife to support you may allow her to feel less useless. But this may or may not apply to you?

Simon - MS Trust: The Info Team at the MS Trust has found that some people say they prefer online groups as this avoids the problems Ian encountered. There are several around, such as Jooly's Joint - www.mswebpals.org

Shen: Hi, I have a question about my Mum. She has not yet been diagnosed with MS but is under a neurologist at the National Hospital in Queens Square, London. She has many of the symptoms, such as extreme fatigue, dizziness, pain etc. The hardest thing I find to cope with is the way she has shut herself off, and I feel sure she is depressed. She upset me last week with a comment when I told her she should change her diet, get more exercise and try a little harder. What do I do?

Kerry - MS nurse: This is a very difficult time. As many people with MS will tell you that often it is difficult to diagnose MS and there are many other things it could be, including stress, depression, or ME. Unfortunately, often it is time that will tell and this causes its own frustrations. It is important that you keep up your activities and especially exercise to relieve some of the tension

Shen: My Mum had a serious fall three years ago - several broken bones and a head injury! They thought at first it was epilepsy, they have now ruled that out as she had no seizures. Then they then ruled out ME and said it was post concussion. Now they are looking into MS as she had some of the symptoms before the accident. She is convinced it is MS after research on the web. Her GP now agrees that it is a possibility. Can you tell me the best test she can have to show this up? She had an MRI over two years ago that was clear. Thank you.

Kerry - MS nurse: Unfortunately there is no specific test to diagnose MS. MRI will show damage to the brain or patches of inflammation but this will only help to support the patient's story. Lumbar puncture is sometimes useful to add further info.

Julia - MS specialist counsellor: People with MS have often told me they hate it when other people tell them how to make themselves better, whether it is yoga, diet, exercise or whatever. It is so hard being the person who has to watch someone you love being ill, when you so much want them to be all right again. I think the only thing someone can really do, sometimes, is to try to understand. This sounds simple but is not. If you were ill, would you be like your mum or would you be different? I find everyone has their own way of reacting. Some shut themselves off, some seek support. It may be difficult to understand someone who reacts differently from the way you would but you might find it helpful if you try to see how different she is from you - which may be extremely hard as she is your mum!

Shen: I have kept away from her for over a week now to see if she will see how much she hurt me, but it seems that she is not sorry. We have always been such a close family - on the phone every day, going out together. All my friends used to say how lucky I was to have such a great understanding mum. She would help every-one. But things are so very different now and I don't know to cope.

Julia - MS specialist counsellor: Oh Shen, it sounds as if you were very hurt. She may have been upset at being told she should try harder - is that really what you said to her? She may be trying as hard as she can in her own way. Mothers often don't know how to help their children cope with their own illnesses. As someone said earlier, they feel a cold guilt at the thought that the child may have to cope with it in any way, either as a patient or as a carer.

Shen: I was so very upset. She sent me an email saying that I should keep my opinions to myself, that sometimes people just want someone to listen and not be so judgemental. Then she wrote a big long list of all her symptoms and how she would give anything to be half the woman she was.

Julia - MS specialist counsellor: Oh dear, it sounds as if your mum was very hurt too.

Kerry - MS nurse: Your mum isn't intentionally ignoring you. She is ill at present, no matter what the diagnosis is, and she can only look after her own needs. This does not mean she doesn't love you. If you contact Barnardo's or the local young carers group they will be able to help you and you can talk your worries and concerns with someone and maybe even meet some other young people in a similar situation.

Shen: I feel as if she has shut herself off. I know she must feel embarrassed when she goes out as she was always known as an outgoing bubbly person - the life and soul of the party. Now she has lost loads of weight, looks very pale and in constant pain. She was always very smart and very attractive. I just want my mum back really and don't know how to do it.

Kathy: I have shut myself off a bit and become quieter. I am also embarrassed when people who knew me before when the symptoms weren't noticeable see me now, so against all advice, I've shut myself off. How can I break out of this cycle as it affects family too?

Julia - MS specialist counsellor: What you are describing happens to a lot of people. It sounds as if you may be a bit like Shen's mum too. I'm not sure how you can break out of the cycle of cutting yourself off. I work with people with that problem, and sometimes counselling seems to help them.

Kerry - MS nurse: I often think the worst problem of MS is the knock to self-confidence and feeling of lack of self worth. This is the MS winning and I know it doesn't help me saying other people don't matter, but this is your perceived impression that people are looking at you. Try to have some small aims and objectives to start with. Go to the local shop for a paper, then reward yourself when you realize that people aren't particularly looking at you.

Kathy: Sometimes just getting access to your family's suggestions is helpful as they can help you break destructive patterns of behaviour. Thanks Kerry, it will help regain a feeling of objectivity.

Kerry - MS nurse: You have made a good start by talking here and realizing there is a problem, now you can start to deal with it.

Kathy: Yes I hope it will prove to be a confidence builder.

John: Like Geoff earlier, I feel like I'm blinded as my partner has had MS for the past four years. The most difficult part for me is that she has always been the backbone of our family - always happy, organising things with the kids, enjoying life - and I can't bear the thought that I may have to take on that role one day and lose her as a support.

Kerry - MS nurse: John, you also confirm that when MS is diagnosed, it is everybody within the family unit that is affected in some way by the diagnosis. And everyone is different in the way they deal with it and come to terms with it. Work on what's happening now and make the most of it, rather than what might not happen in the future.

Julia - MS specialist counsellor: Both Shen and John are suffering from a serious loss. Naming what it is you have lost is important, and you have both managed to do it here. When you've named it, you can look at it.

Kathy: I found that diagnosis required a period of adjustment by all the family.

Julia - MS specialist counsellor: It is very distressing when you have lost someone who took care of your life in some way. Loss requires a grieving process, which often involves anger and frustration, when you rail against the loss – NO, it can't happen! You don't WANT to lose your wife/mum as she was! And with MS, of course, the loss may only be temporary, but when you've been angry for long enough you begin to find other ways of dealing with it. If things have to change, they will, and you will, and you will learn that you can bear it. Often people need help with this transition, particularly if the anger is being directed at someone else where it doesn't belong including, such as in the family or at work or even at the person with MS themselves.

Kathy: I agree with Julia - you need to deal with that and the MS patient's frustration at not being able to do what they did before.

Julia - MS specialist counsellor: Eventually you learn how to live with it. Sometimes people prefer to be angry rather than be sad. This may be happening in Shen's family too currently?

John: Anger has been a difficult one for me to lose. I eventually left my partner due to feeling that I was caring for her more than I was loving. But I'm trying to deal with it all so I can go back and enjoy life. But I have my own issues to deal with.

Julia - MS specialist counsellor: It is very hard for everyone when relationships break up.

Kathy: It's a radical change in how you thought your life would be.

Julia - MS specialist counsellor: Grieving processes can cover up loving feelings.

Shen: That's how I feel – angry. I feel that I have to keep away for my sanity. My younger sister is no help whatsoever! I have always been the one that has been there for our mum and it's me she turns on.

Julia - MS specialist counsellor: Illness challenges our ideas of the way we want to be; ideas of caring and being cared for; of our relations with others and with ourselves.

Kerry - MS nurse: I think it's really important for everybody to do something they enjoy be it a quiz, sports, tapestry, whatever - just something to chill and reduce their personal stressors. Remember you are all important people.

Kathy: Although you promise to love someone in 'sickness and in health', I think that most people don't understand what that really means.

Julia - MS specialist counsellor: It's often the nearest and dearest who get the brunt of angry feelings in one way or another. Some people are really disturbed by illness in their partner or in a parent, in a way they hadn't expected.

Kathy: We are only prepared for a healthy, normal life really - do the MS specialists find this?

Julia - MS specialist counsellor: Absolutely, Kathy. Except that some people were brought up by someone with a disability or illness, and they are prepared - either in a positive or a negative way. I worry sometimes for children who find themselves reacting in ways they didn't want to react. They can feel they are bad people because they have bad feelings about the person with MS. The really bad thing is that MS exists. Ordinary mortals have to cope with that as best they can.

Kerry - MS nurse: I agree Kathy, any chronic illness brings its own pressures and uncertainty.

Julia - MS specialist counsellor: It's OK to have bad feelings about your parent if they are healthy, but much more guilt-provoking if they are ill. And yet it is important to be able to separate from your parents in order to grow up, and this often involves acknowledging bad feelings (preferably alongside loving feelings those these may be hidden).

Kathy: It is so hard for children when their peers don't understand either.

Shen: I'm now worried that my mum might have a fall and not tell us. She has done this before and ended up in A&E. She says she doesn't want to be a burden. I feel like I'm in a no win situation. Do you think I am selfish and uncaring by keeping away?

Julia - MS specialist counsellor: I want to ask you how old you are, Shen! Not sure what difference it makes, since what you are describing can affect any child at any age. But the younger you are, the more you may worry and the more upset you may be?

Kerry - MS nurse: I think the new book *The Young Person's Guide to MS* will prove helpful for both Shen and others with a parent MS as it shares some of these feelings and shows that you don't have to be alone.

Julia - MS specialist counsellor: Children (of any age) often want to keep their parents healthy by holding onto them, both 'inside themselves' and in the outside world. Mothers don't always recognise this.

Kathy: I think it's a dilemma for Shen - she wants to not get enveloped and maintain a degree of distance but she's also worried about appearing selfish. It seems quite understandable to me but she shouldn't feel guilty.

Julia - MS specialist counsellor: Sometimes children almost try to BE their parents - to take over, in order to keep them safe. Their parents aren't always very keen on this and want their own lives and want their children to have their own lives. I am sorry it's so hard for you with MS. It can be very hard to work out how to show you care. Parents don't always realise how much their children care and they don't want them to care as much as they do. It's all so painful when parents are supposed to make their children happy and ok, not make them unhappy and worried.

Kathy: it's a kind of role reversal that parents are not very keen on. You always feel a degree of responsibility for your children. And I suppose you forget that they feel the same about you too.

Julia - MS specialist counsellor: Just for the record, Shen, you are clearly not selfish and uncaring or you wouldn't be in this chatroom now. Your problem is how to use your care and your loving feelings for your mother in a way which works for you and for her, and your mother's problem is probably the same - how to use her care and her loving feelings for you in a way which works for you both. With MS there are no simple answers, but good on you for trying!

Kathy: Don't feel downhearted Shen, you are taking positive steps in this chatroom and working your feelings through. It's more than some people do.

Kerry - MS nurse: Unfortunately teens especially also take on a degree of responsibility for their parents.

Kathy: Yes I agree - teens think about issues more carefully.

Julia - MS specialist counsellor: Teens also beat themselves up for failing to make everything better too. Sometimes they want to run away because they feel it is all too much. When you are worrying FOR someone it can get overwhelming and too much, so you may have to leave. Or you can find a way of letting some of it go so that they can worry for themselves instead, and you can stay.

Kathy: Signing off now - appreciate the chat - keep your chin up Shen - bye and thanks!

Shen: I'm amused to see you all assume me to be a teenager! I am 27. I have a highly stressful in investment banking and do get very stressed out and work long hours. So when I get emails in the day from my mum saying she is ill, I get angry as I can't do anything and also I worry then. Thanks for saying you don't I'm selfish. That made me feel better.

Julia - MS specialist counsellor: It's the dilemma people with MS have - how to let people know what is going on without causing them more worry.

Shen: Would it be ok if I suggest to my mum to come into this chatroom? She may tell me to mind my own business, but it's worth a try. I don't really think she will say that.

Simon - MS Trust: The chatroom is just today (until 7pm), though your mother is welcome if that's possible. There will be a transcript available on our site in a few days. Though from what you say, the chance to talk with someone might help her. There are other online groups such as Jooly's Joint (www.mswebpals.org) and MS People UK (www.mstrust.org.uk/mspeople).

Kerry - MS nurse: Many of the feelings that are being discussed are similar for any family living with chronic illness although there has to be some caution as your mum is not diagnosed with MS.

Shen: May be you're right, as she has not been diagnosed it might not help her. Thanks you for all your help, and listening to others has helped. Keep up the good work. Take care.

Joanna: Anger was the thing for us. We seemed to be dealing with the practical implications of MS, making the house work for me, getting what was needed etc. Then we both became angry and were at each other all the time. I realise now it was the MS we were angry at, but we took it out on each other.

Julia - MS specialist counsellor: I am sorry. I wish there was a way we could help people not to do this. MS can make people so angry, in so many ways.

Kerry - MS nurse: This is very typical within relationships, and so difficult to realize that it's MS to get angry with and not each other. This is what I try and explain in the workshops for kids and also in the new booklet it is explained quite nicely.

Joanna: I recognise some of myself in what Shen was saying about her mother - there was almost something that made me want to make others lives difficult because mine was.

Julia - MS specialist counsellor: that feeling of wanting others to know how you feel by making them feel the same is so common.

Kerry - MS nurse: Good point.

Joanna: It wasn't premeditated, but looking back I can see how I sort of manipulated things and gave no easy options

Julia - MS specialist counsellor: It fights with the feeling of wanting to care for them. I'm interested in what you said about manipulating things. Manipulation can be a response to loss of power. MS often reduces sources of power, either in real life or in imagination.

Joanna: Are there ways you advise people on how to avoid anger - or is it a matter of finding other routes to burn off their resentment safely?

Julia - MS specialist counsellor: I don't advise people to avoid anger. I sometimes try to help them to understand where it comes from and where it can usefully be directed. For example, getting angry at your leg for not working may result in you hitting it, which may not be terribly helpful. Whereas writing to the Primary Care Trust to ask for more physiotherapy may be a better way to direct your anger. Resentment is a bit more complicated, I think. It can have so many roots it can be very damaging to relationships. Resentment can be a reaction to someone else being OK when you aren't and that can be horrible - you end up wanting them to be no better than you. Anger is almost cleaner than resentment. But it can be helpful to work it through with someone who understands - I'm back to recommending a counsellor again!

Joanna: I think that was what happened. Misdirected anger that did nobody any good.

Julia - MS specialist counsellor: Sometimes the anger is actually to do with something from the past. The current situation is too like a distressing one from the past. So the anger is really directed wrongly; at the current partner instead of a past person who has long gone or moved on

Joanna: Our response to MS did highlight every crack in the relationship, and things that would have been sorted out became points of conflict. And at the time neither of us recognised that it was fear and resentment of MS that was

driving it. We were both frightened of the MS, but instead of uniting, we fought each other.

Julia - MS specialist counsellor: This is such a recognisable story. It is so sad. When couples can recognise they are in it together, that both are suffering, they can sometimes band together over it, but often this doesn't happen. It is so easy to avoid mentioning the MS too, even if you think of it, so it can be very hard to acknowledge that it is unspoken fears about MS, which are underlying the fights. One of the common fears is about whether you are still loveable, and fighting each other may test this one to destruction.

Joanna: MS, or probably fear of MS, is quite an abstract thing. It was sadly easier to take it out on an easier to see target.

Julia - MS specialist counsellor: The one with MS can also sometimes want the other one to leave - to 'save themselves' without recognising it and without realising that they themselves are more than just 'a burden' or 'the MS' and that the reason the person chose you in the first place probably still stands. The other problem is that it's also not just the MS, but how you react to it, which can cause problems and people don't always understand why someone is reacting in the way they are.

Kerry - MS nurse: By having a chronic illness such as MS in the family often either brings partnerships closer and makes them stronger, which it sounds as though Joanna is now doing, or like John earlier it can widen the cracks and split the relationship.

Julia - MS specialist counsellor: Sometimes people do end up punishing each other because they feel they are being punished themselves, whether by having the MS or being attached to someone who has it. To go back to the problem of anger, sometimes depression is a sign of hidden anger, and it can be very difficult to live with someone who is depressed because you can get shouted at when you try to help. Depression does need to be attended to, whether by the doctor or by a counsellor or psychotherapist. In my experience, anger does often respond to counselling, and it reduces over time anyway when it is part of a grieving process.

Josephine: Hi, I have had MS for eight years. We are both in our 50s. My husband has been medically retired with a degenerative hip problem for ten years. At the moment he refuses to have replacements in case it makes our situation worse, and he won't discuss it with anyone. We are managing fine between us at the moment but he could improve the quality of his life but I can't make him see that.

Julia - MS specialist counsellor: That struggle about what cure to take and what to refuse is such a potential source of family conflict. It is so common. It seems so obvious to one person that A will help, when to the person concerned it feels much too dangerous and B is obviously much the best option. Emotions can run very high and people can get very cross with each other for not trying to get better, when it isn't nearly as simple as it seems.

Josephine: What if the depressed person refuses help and can see no positive future?

Julia - MS specialist counsellor: This is a very difficult one. Many people do refuse help. The whole problem of the reason for existence is such a difficult one.

The philosophers have struggled with it. In my experience many people need to know they matter to someone else, but if you are depressed it can be difficult to believe that anyone else cares or that they matter if they do. If the depressed person won't go for help and you care about them, I suggest you go for help yourself. You may find that is enough to make it bearable and it may even help them too. At least they will see that you are OK and they won't have the added guilt (even if they want this) of knowing that you are suffering more because of them and you may find other ways of helping them or of reducing their problems.

Josephine: Thanks Julia. We have been married nearly 30 years! We also flare up and say hurtful things but in some way it helps and, as I said, 30 years can't be bad.

Julia - MS specialist counsellor: Some people can cope with angry words, others can't. It sounds as if your relationship can.

Sian: Hello, I have relapsing/remitting MS and have been diagnosed for three years. I have a problem with mum, who is now my official carer. She thinks I should have 'treatments' to the extent she is planning it all for me. I don't think I need anymore treatment at the moment. I also think she could do with talking to someone like an MS nurse about her feelings. How do I approach that?

Julia - MS specialist counsellor: The problem of someone else 'knowing' what is best for you. Presumably she is desperate for you to get better and can't see the you out there for the one in her head, if you see what I mean?

Kerry - MS nurse: Mums always want the best for daughters. If anything hits the newspapers about the 'most recent cure/miracle', we get inundated with hopeful queries from mums that their son or daughter could be treated. We all need hope, and much research is being done, but at present until we understand more what is happening in MS there is no cure. Our general aim is to provide education and to encourage the person to look after themselves as well as possible by general healthy diet, exercise and activity to keep joints and muscles moving, stress management techniques and some relaxation. The aim is that if the body is as good as it can be, it will have more energy to deal with the MS problems.

Sian: Thanks Kerry. Do you think it would be helpful for her if I contacted the MS nurse to find her someone to talk to? She is a retired nurse herself and should know better :-). But she's probably frustrated and I don't know how to help her.

Kerry - MS nurse: yes I'm sure if mum gives the local MS nurse a ring, she will have a chat with her.

Cid: I got terribly, terribly angry with my partner and said lots and lots of really, really horrible things to him. I told him that I really did not mean this and that it was just frustration, related to my MS. Think I hurt him quite badly because he has his own problems. What should I do?

Julia - MS specialist counsellor: Oh Cid, you have got a problem. You are right, people can be very hurt when you say things to them in these situations. It can be a problem with 'deciding to be honest', because it seems honest at the time. Afterwards you see it was only part of the story, and not a very good or entirely true part either, but it is so hard to take back words you have said. I'm not at all sure what you can do, Cid, but I suspect you know.

Cid: Yes Julia, I agree. It is so hard to take back words you have said, even if you did not mean any of them. Fortunately, my partner is extremely understanding but forgiveness? Unsure, as yet.

Mo: Our biggest problem has always been what do we tell our children? Symptoms are minor - fatigue, bouts of dizziness, slurry speech when tired - so it's not a day to day problem at the moment. Tell or not tell? If tell, are there good ways?

Kerry - MS nurse: What and when to tell the children is difficult and usually depends on the age of the child. The younger ones tend to be very matter of fact. You worry about what to say and when you eventually do, they just say OK.

Julia - MS specialist counsellor: Children do need to be told something usually, or they make it up for themselves and get it seriously wrong. You might find Kerry's or my books useful (see links at the start of the transcript). You may be able to start by trying to find out what they know already. When I have worked with parents and children, it has been striking that the parents actually had no idea what their children thought about the MS or the symptoms. The children often had their own ideas, which parents could easily correct like 'daddy got MS because he went potholing' or 'daddy is lazy because he doesn't help mummy to lay the table'.

Kerry - MS nurse: Generally, open the door and invite them to ask questions when they want. The saying "My Ms doesn't affect the children" is usually wrong as children are affected by MS, even if indirectly. They notice tiredness and think you are not interested or they say you're always grumpy or are worried to increase stress as that makes you feel worse (see comments on anger earlier).

Julia - MS specialist counsellor: Children sometimes don't ask questions because they are afraid of the answers, or of upsetting the parent (which may to the child mean something much worse than just 'upsetting').

Al: Kerry, I think your new book is great, but I'm not sure how to bring it up with my daughter. She's 15 and says she doesn't want to know about MS (though at 15, she doesn't want to know full stop quite often). Not sure how to give her the book in a way that won't lead to conflict. Is MS taboo, or is she coping in her own obscure teenage way?

Julia - MS specialist counsellor: I agree it can be very hard to talk to 15 year olds. Is there anyone else can talk to her? You or her father may be the last people on earth she can talk to just now. Have you tried talking to her school teachers? They may be able to help or some other adult she knows and trusts?

Kerry - MS nurse: Al, thank you for your comments on the book, which is mainly written by teens and therefore is for teens. Yes you are quite right, there is normality there. Just give her the book and say its there to dip into if she wishes, but don't push it.

Julia - MS specialist counsellor: It is so unfair for a 15 year old; she should be the centre of her world, just now, not you. She should be looking outside the family, not in. Your MS will face her with terrible conflicts about divided loyalties when she should be thinking about leaving home and all the mixed anxieties about wanting to have a life of her own and at the same time wanting to be a

small child for ever - wanting to grow up and not wanting to grow up. Having a mum with MS may raise all kinds of unrealistic anxieties for her and teenagers quite reasonably don't want to think about these things, they just want it all to happen as it should. It's the same as the problem earlier about going to the MS Society and seeing other people who are worse - if you can't bear to know about frightening things you can't get reassurance. I would probably want to make sure your daughter knows a) she is unlikely to get MS herself and b) if she does, she can still get married and have children. Also that MS is unlikely to kill you before she is grown up and has a family of her own. But that's just my list of things every child should be told, like it or not. I'd love to know what other people think!

Kerry - MS nurse: I agree teens are normally self-centred and her main worries are how your condition will impact on her eg if you die, will she get it. On the other hand she genuinely might not think MS is a problem. I think both issues are addressed in the book - at least it's a starting point.

Al: I think she's less worried about her own family, but more about being embarrassed by me as a mum. I suppose at least me reeling around with a stick gives her an actual reason to be embarrassed, rather than just by being her mum :-).

Kerry - MS nurse: Al, I think you're right. The comment made me smile.

Julia - MS specialist counsellor: You sound like a good mum, Al! It's that awful "you can't go out looking like that!" that we said (or wanted to say) to our own mothers. I suppose mums are like iPods - you want the best looking one as it reflects on you? Shame we can't all be that beautiful. But seriously, the embarrassment thing is important; it can be hard for everyone. Sometimes it's to do with the feeling of 'a healthy mind in a healthy body' - that if you LOOK bad you must BE bad or weak or vulnerable, when actually of course, appearances are often deceptive. Teenagers are struggling with that, signalling to each other by their appearances and not at all sure about how good or bad they are inside, and whether it shows or not.

Shen: This is just my opinion, but with regards to the teenager, I think you should get her when the mood is right - when is she at her best eg mornings, evenings. Or go shopping together and have a pizza, then you can gently speak to her about your MS, and let her know that it hasn't changed your feelings of love for her, only your ability to do things. Just a thought!

Al: I'm forever on the look out for the chink in her armour that allows me to get through :-).

Julia - MS specialist counsellor: Good idea, Shen. Though parents don't just love their children, and the MS might make the children more irritating or frustrating or unlikeable. Heretical thought, sorry! Love and caring, yes, but also annoyance and frustration and sometimes downright dislike.

Kerry - MS nurse: Al, don't be so hard on yourself, providing underneath she knows you're there if she needs you.

Shen: Al, don't give up looking. It is there you just have to find it. But the worst thing is to try too hard. By that I mean keep on at her every chance you get. Leave it for a while and then pounce when she least expects it. You sound like a great mum. Good luck, take care.

Julia - MS specialist counsellor: Relations with parents often seem to improve after the age of 30. It may not be until she is a lot more grown up that you can really talk to her about the MS. Some people can, some can't. I've never worked out what makes the difference.

Al: I suppose that's the thing, isn't it. The maternal instinct is to worry that she's cut up about the MS - whether it's concerns about me or concerns about her own future. I don't want to force her to consider the MS, but equally I don't want to leave her exposed to wayward ideas or lack of information. Being open and honest and available is the best approach - patience is so necessary with a 15 year old!

Kate: Just wanted to tell you about the Stepping Stones approach to unrecognised grieving. It is a learning and support group workshop developed by a GP and being piloted in my area. Found out about it through PALS [Patient Advice and Liaison Service - each primary care trusts and NHS trust in England has a PALS]. It is about understanding the emotions that come with disappointment and loss and one's individual way of reacting so can choose to react differently. It also aids communications with others. It is really a life skill about dealing more positively with losses so can reclaim the energy emotions take. It can also be a self-help method.

Kerry - MS nurse: That sounds an interesting project, maybe a bit similar to Expert Patient courses.

[Stepping Stones is a course that allows people who have become depressed or emotionally distressed as a result of chronic illness to explore the feelings of grief that they have and help to make overwhelming emotions understandable. The courses are run by Realisation Training in Devon - office@realisation.info / 01752 892455]

Jan: I wonder if anyone has any practical advice on how to offer help and give help - as well as how to accept help graciously!

Kerry - MS nurse: Tough call, Jan. Over to those with MS and have the experience

Julia - MS specialist counsellor: Asking for help and accepting it is one of those things we have to learn as we get older. It is such a challenge to our sense of omnipotence - the 'I can do anything' feeling a child has - and it means we have to recognise we need other people when they can be so infuriating and useless, and they have such a power over us. I have a concept of 'mature adult dependence' (unfortunately the acronym is MAD). There are ways of asking for help which involve being mature and adult, not childlike. Mutual dependence is a perfectly adult way of carrying on a relationship. When we ask for help or offer it we can do it as adults, respecting the other person and their needs, as well as our own. Does this help?

Julie: I was diagnosed four years ago. Since then my marriage has collapsed and it's now just me and my son. I've been lucky in that my MS is very mild and I rarely have any physical symptoms. My son is 8. Do I tell him about the MS or wait until it might affect me in some way and then try to explain what is wrong?

Julia - MS specialist counsellor: At the beginning of this I mentioned both Kerry's and my books, you might find either or both of them helpful. It can be helpful for children to know that MS does not just mean 'something wrong' or 'the wheelchair', because that arms them against hearing about it in a situation where it does mean that. So if you can tell your son you have MS, and tell him what it means at the moment, for example, that it makes you a bit more tired than other mums, but not much else, it may be helpful for him. You don't want him finding out from a doctor's letter and from a soap opera, which has a worst case scenario.

Kerry - MS nurse: I explain MS as the 'message system' that gets mixed up. It's worth saying something when you are well maybe about a time when your legs were a little wobbly or something, but reassure him that you are there for him. There is a book Benjamin published by Schering Healthcare that is quite good. It relays a story about a little boy who finds out about his mum having MS when she has a relapse. It may be quite good to go through the pictures with him.

Julia - MS specialist counsellor: And as I said before, I would always try to find out what your son already knows or remembers, eg about a time when you were diagnosed. In my book, I described an 8 year old who remembered her mother going into hospital when she was 6, and was still cross with her mother for sending her grandmother to fetch her from school. She hadn't told her mother in two years. When they talked about it, it changed.

Kerry - MS nurse: The fear of hospitals and maybe somebody dying in hospital is often a big concern for younger children.

Julia - MS specialist counsellor: I agree with Kerry. The really distressing bit was hearing children who thought it was their fault in some way that their mother had MS.

Kerry - MS nurse: This is similar to a mum's guilt that her child has MS. As many mums are diagnosed within six months of a baby, I have also met children, even in their 20s, who have this feeling of guilt that they caused their mums MS. Same reassurance given - it is nobody's fault.

Julia - MS specialist counsellor: I blame that first Viking. There is a theory that MS started with Vikings who travelled the world on their boats. The spread of MS just about matches where the Vikings went. So it is the fault of that Viking who fell in love with your great-great-etc grandmother!

Mo: Kerry mentioned the Benjamin book, but the other books mentioned sound like they are for older kids or adults. Do you know of any other things (books, web, etc) for under 10s?

Kerry - MS nurse: There are two good websites. The American National MS Society (www.nmss.org) has Keep S'myelin especially for younger people with MS parents. Also the Canadian MS Society (www.mssociety.ca) is good, although occasionally there may also be young people with MS. They are both interactive and fun with games etc.

Julia - MS specialist counsellor: My book talks about helping children of any age. It was meant for parents originally, and was published by Penguin under the title; 'My Mum Needs Me'. With small children play is often a good way of finding out what is worrying them, if anything is.

Simon - MS Trust: There are two books from the MS Trust - My Mum's Got MS and My dad's Got MS. Both tell a simple story to raise a few basic ideas about MS for the under 10s (see the publications list at www.mstrust.org.uk/publications).

Jude: I have been reading all the comments with interest as I feel able to identify with a lot of them. And I would just like to say that both of my children who are now aged 32 and 30 are very supportive - in fact sometimes overly so. But they were both very distressed when I was diagnosed six years ago. I gave them as much info to read as I could and also talked to them. My husband has been wonderful, and takes every new problem in his stride. So my experience has been that my family and friends have all been very supportive. I know not everyone does not have this.

Kerry - MS nurse: I'm really sorry, I am going to have to leave now. For me this has been a really interesting morning and I hope it provides some use to all families affected by MS.

Simon - MS Trust: Kerry, thanks for your input.

Julie J: I've only just come online so you may have covered this already. Loss of sympathy. My husband has what he calls 'compassion fatigue' and has now embarked upon an affair, which looks like ending our marriage. Any advice?

Cal: MS has been quite divisive. We used to do a lot of sport together, but that's no longer possible. We no longer seem to share the interests and life-style that brought us together. Sometimes I think we'd both be better off if we divorced but feel guilty for this thought.

Julia - MS specialist counsellor: Ow, Julie, I imagine it hurts. MS can certainly threaten relationships, and it sounds as if this is happening for both of you. It's difficult to know what to say to either of you. Relationship counselling may help. Carers sometimes don't know how to ask the person with MS for love and support. They may be too busy protecting them to recognise their own needs in the relationship and they may feel they need to seek help outside rather than risk damaging the person with MS by asking them for support. But this may not be your problem at all.

Julie J: I don't want a divorce partly because I value our marriage but also because I rely on him for help and could not manage without. But now he is out half at least of every day so I can't see how the future will work out.

Julia - MS specialist counsellor: Divorce may be a good thing in some situations, though it can be terribly hard for children if you have them.

Julie J: One only - and away at university in the final year and very distressed by it all.

Julia - MS specialist counsellor: Sometimes people separate but continue to care for each other, just in different houses. But this may not be right for you, Julie.

Cal: Julie, your situation sounds horrible. As far as I know, there's no one else involved in my marriage, but we have gone down such different paths that we are no longer the people we were and the marriage is a sense of habit rather than a relationship.

Julia - MS specialist counsellor: Habit can be a good basis for a relationship too. I suppose my concern for Cal would be that neither of you may be quite aware of how much the relationship brings you until you lose it.

Cal: It seems so hollow now

Julia - MS specialist counsellor: Have you tried Relate (www.relate.org.uk / 0845 456 1310), Cal? It's difficult with divorce. You may both be better off finding someone else, but the statistics as far as I understand them, suggest that usually one person ends up better off, but the other one doesn't. So it's a bit of a gamble. I said earlier that sometimes people can cope better if they can separate in their heads. Your husband may need to find a way to separate from you in his mind, for example, to sort out how responsible he is and how much you can take care of yourself, or have other people take care of you. Julie, men so often have affairs when their children leave home - is it a kind of midlife crisis? Compassion fatigue sounds so distressing. I want to know if you have compassion for him, or if he doesn't see this?

Julie J: We're in theory coming up for our silver anniversary and there's bound to be some 'habit'. But for me, feelings remain and I am angry that my MS has largely brought this situation about.

Julia - MS specialist counsellor: Is it the MS or your reaction to it? Or his reaction to it? Because reactions can sometimes be changed. The 'two year rule' may be important too. It often takes people two years for their mind to catch up with their bodies, for them to go through a grieving process and come out the other side. So it may be that things are worse after a new symptom, a new loss, but that they will get better again.

Julie J: He says he is fed up with having to do things for me because of the MS. Mind you, he's taken up with someone who also has a chronic condition. It's as if the MS has become boring but another illness is OK and can be tolerated.

Julia - MS specialist counsellor: I wonder if he feels more responsible for your illness, and the advantage of the new person is that there is no way he can feel it is his fault? If that is the problem, you may be able to help by making sure he knows you don't hold him responsible and you share his anxiety that is someone's fault. Am I making sense to you or not? Is it what he actually has to do for you, or the sense of responsibility he feels? Either could be changed perhaps. Do you blame someone for your MS?

Julie J: The responsibility I think, together with the tie it imposes on him when he wants to be doing other things. No I don't blame anyone. It's the luck of the draw.

Julia - MS specialist counsellor: If he could be persuaded to seek counselling he might find the sense of responsibility could be reduced. Is there any way of addressing the 'tie' issue, such as getting other people in to help? The problem is

that it is nice people who feel such a huge sense of responsibility, and then can't bear it.

Julie J: Not really, they are small daily type chores or perhaps lifts to see family etc.

Julia - MS specialist counsellor: I don't know if you can help him to feel less responsible and less tied. Does he have 'time off' when he knows he won't have to do anything for you? Sometimes there are practical things one can do. Sometimes it is so much in the person's head that nothing you suggest works. Small daily chores and lifts can feel like they take over the whole of life.

Julie J: I agree on the 'nice' people as witness the fact he has another disabled partner now - but it doesn't make the behaviour to the first person 'nice'.

Julia - MS specialist counsellor: I agree. MS can make the nicest people behave in a horrible way. Sometimes you can understand it, but it can still hurt. It hurts both the person who has behaved badly and the one they behave badly towards.

Julie J: Thanks Julia. Goodbye.

Julia - MS specialist counsellor: Sorry I couldn't help more, Julie.

Julie J: That's fine - its cathartic to talk!

Julia - MS specialist counsellor: I'm off now, thanks for inviting me to join, Simon. I've found it very interesting reading all the comments and having a chance to have my say too. Best wishes to all of you. Hang in there!

Simon - MS Trust: Julia is be leaving us now and Jane and Kate, both MS nurses, are joining. Does anyone have any questions or comments for them?

Steve: Hi. Has anyone talked about sexual problems in a relationship?

Jane - MS nurse: Hi Steve, if you would like to talk about sexual problems please do.

Steve: Our sex life has rather ground to a halt. My wife finds intercourse painful and has lost interest in the physical side of things. Is this something that happens in MS and can you suggest anything that might help us? We've been married six years and she was diagnosed five years ago.

Kate - MS nurse: Sexual problems are quite common in MS. There are lots of reason why sex can be painful but with MS, women can suffer from loss of lubrication and it might be that this is a factor.

Jane - MS nurse: Have you tried talking to her about it, or is that something she doesn't really want to do? It may well be associated with some of the symptoms your wife may be experiencing. She may be very fatigued, which is very common in MS.

Steve: It feels like it's part of her life she's trying to close down. I know she feels very self conscious about the way she walks now - doesn't use a stick by does limp noticeably - and I think she's beginning to see herself as a little old

woman (she's 38!). It's not that she won't talk, but I think her view of herself no longer really involves a physical side.

Chrish: Hi, yes, a similar issue. I was diagnosed shortly after our marriage ten years ago. Now so-called normal sex is not an option but my wife feels anything else is artificial and avoids.

Steve: It's a big problem, isn't it Chrish.

Kate - MS nurse: Even if sex is difficult or off the agenda it is important to carry on the intimacy and lines of communication. People can often have a low self image and lose confidence. The MS Society do a good booklet on sex and intimacy (MS Essentials 12: Sex, intimacy and relationships – ring the MS Society on 020 8438 0700). Maybe a psychosexual counsellor would help?

Jane - MS nurse: It may also be to do with how she is feeling inside herself. Do you think there are times when she can feel low and tries to put a brave face on things? Having the opportunity to talk to a professional with regards to how she feels may help matters. It is also very likely she doesn't want to burden you with her feelings.

Steve: She sometimes feels a lot of pain around the tops of her thighs and I think fear of this adds to the problem.

Kate - MS nurse: It could be spasm or nerve or muscle type pain. Might be worth talking about it to her GP, neurologist or MS nurse. Also you could try exploring different positions that don't put pressure on that area.

Jane - MS nurse: Is she having anything for her pain? It may well be a physical problem she has that can be resolved. A visit to her GP or talking it over in some detail with her MS nurse or neurologist may help to resolve the problem.

Steve: There is always the underlying fear that it's something to do with oneself. This sounds rather self-centred, but her disinterest in sex (for MS reasons) undermines my own self confidence.

Kate - MS nurse: No it doesn't sound selfish. It's an important part of relationships and affects our self esteem and well being. Have you managed to have a good chat about the way you feel with our wife? Your wife might feel under pressure and guilty about it. Could you perhaps agree to put sex on hold for the time being and concentrate on feeling close and building up affection and intimacy without it having to lead on to sex? It might then develop naturally.

Jane - MS nurse: Sexual problems like this are extremely common, Steve, and need to be talked through to identify the many potential issues that could be contributing. In my experience it is not a personal issue with the partner that is the problem.

Steve: It seems to be a difficult topic to talk about meaningfully. And the longer it goes on, the more difficult it becomes.

Jane - MS nurse: It might be worth trying the dating game like you used to before you were married. It might help with her self-consciousness and how she feels about herself.

Steve: Are psychosexual counsellors something provided by the NHS?

Kate - MS nurse: They are in some areas but if not, Relate (www.relate.org.uk / 0845 456 1310) usually have one. Your GP or MS nurse might be able to tell you if there is an NHS psychosexual counsellor in your area.

Jane - MS nurse: Alternatively you could contact the British Association for Sexual and Relationship Therapy (www.basrt.org.uk / 020 8543 2707). They offer advice and have a list of accredited therapists.

Steve: Kate/Jane, thanks for the ideas. Chrish, how have you and your wife tried to deal with this problem?

Chrish: It's become an area of frustration and failure to both of us - of inescapably not being 'normal' - and grievances smoulder on both sides.

Kate - MS nurse: Have you had any help or spoken to anyone about your difficulties with sex?

Steve: I'm worried that my wife has accepted this as the norm, and that it's a consequence of the MS. I try to be very understanding and adapting but feel frustrated that my own needs aren't being met.

Kate - MS nurse: Even if full sex is not possible, it is still possible to have a close sexual relationship that fulfils both of your needs. Her sex drive may have taken a nosedive. It is possible to resurrect things but you have to perhaps start from scratch.

Chrish: I am very much talking inclined, used to visit Julia when in UK years ago, sad I missed her earlier in the chatroom. But my wife's not comfortable with that. Steve, what you say rings a bell. And the pressure around the whole issue scares me off.

Jude: Hi. I also have problems with sex. Its due to loss of feeling sexually and also I have put a bit of weight on due to not being as active. I am now starting to lose the weight but I don't feel attractive sexually, although my husband assures me he still feels the same way about me that he did before I became ill.

Kate - MS nurse: Hello Jude. Do you mean loss of sensation or not feeling sexual anymore?

Jude: I mean loss of sensation.

Kate - MS nurse: Sexual problems are often a combination of physical and emotional causes. Have you had any medical input, as there may be treatments available to help?

Jude: I don't feel able to discuss my problems either with my GP or MS nurse.

Kate - MS nurse: Most MS nurses are well aware of these problems and are willing to discuss them. I can assure you, you wont be the first. We have heard it all before! Try to use her as she may have some ideas to help.

Jane - MS nurse: Knowing more about how MS symptoms can affect relationships can help to break the barriers and make it easier to discuss things.

Kate - MS nurse: As regards loss of sensation there are a few tips. Apparently research into this area says that women with sensory loss need more vigorous stimulation to become aroused, and might respond to different types of pressure/

vibration/ extra fantasy etc. Some warming lubricants (such as Sensilube), minty shower gel and clitoral stimulators such as Senselle (available at Boots!) can also help. If you are too embarrassed to go to the chemist then online shops such as Ann Summers etc are more discreet.

[there is a list of links at the end of the Open Door article on sexual problems from August 2003 – available from the MS Trust]

Jude: I have tried something called Zestra, and it does help. But I don't feel able to discuss the problem even with my husband, although I know he will be supportive. This is a symptom that I never knew would happen. And it makes me feel less of a woman. Especially as I had a very good sex life prior to MS.

Jane - MS nurse: I am glad you find the Zestra helpful. Why do you find it difficult to discuss it with your husband? Addressing sexual issues can be very individual and can be contributed to by several factors. MS nurses would be more than happy to help you and discuss with you whatever issues you would like in a sensitive way. Everybody is different.

Jude: I have always had problems discussing anything intimate. It's not a problem that my husband has as he can discuss anything. The only way I have found to start to discuss it is to leave my MS book open at the page that discusses sexual problems. I know my MS nurse would help but I feel unable to discuss it with anyone.

Kate - MS nurse: It is difficult if it doesn't come easily to talk. Nurses are so used to speaking about bodily functions it becomes second nature. When you have been with someone for a long time you get into sexual patterns. With MS on the scene the usual sexual routine might not work for you any more.

Jane - MS nurse: Does that help in any way? Does your husband have any idea as to how you feel?

Jude: I don't think my husband has any idea how I feel. I can't discuss my feeling at all as I begin to get upset and tearful.

Kate - MS nurse: If this happens, you both need to start all over again finding out what works and what doesn't. It can be fun!

Jane - MS nurse: From his perspective do think sex and intimacy is an issue?

Jude: He doesn't think sex or intimacy is an issue and he has said he is willing to wait if I feel unwell or fatigued. I do feel better having discussed it on this chatroom and feel more able to discuss my feelings like this.

Jane - MS nurse: Maybe communicating with your MS nurse via email is a way of helping you, but you still need to be honest with your husband. I am sure if he understood how you feel, that would be so much easier for you.

Mary: Sexual problems seem to be cropping up a lot. My boyfriend and I split up whilst I was being diagnosed and this together with the effects of MS on how I feel about myself make me fear I'll never meet anyone again.

Kate - MS nurse: That must have been a massive blow, losing your relationship at the same time as being diagnosed.

Mary: Not really a golden period of my life, no. If I'm rational, I can understand why he went, but it just took the floor out of my world.

Kate - MS nurse: Diagnosis is such an unsettling period and does rock your world. Maybe he was unable to cope, so don't blame yourself or the MS. Just because this has happened to you doesn't mean that everyone you meet in the future will react in the same way. In my experience there are a lot of very supportive men out there. I know lots of people who have met their partners after diagnosis, and in fact we have had a few weddings this summer!

Mary: During the bad periods I've been incontinent and had to use a wheelchair. I'm still easily tired and can sound drunk and wobbly sometimes. I'm OK in the day to day, but think I'd be very reluctant to get intimate with someone.

Jane - MS nurse: Have you had any contact with an MS nurse since you were diagnosed. Understanding as much as possible about your symptoms and why they occur can help you to feel more in control.

Kate - MS nurse: Have you had any help with managing your symptoms from either an MS nurse or neurologist? Continence problems especially can be successfully managed.

Mary: The continence and the wheelchair were really only during the relapse, but it knocks your confidence in your body when it does this to you.

Kate - MS nurse: It's very common for MS to knock people's confidence. The uncertainty of how and when symptoms will occur can be difficult to cope with. Perhaps you could work on things that boost your confidence - a new hairdo/ learning something new/ time with friends etc. In the right relationship your confidence will probably grow anyway.

Mary: I think you're right, Kate. I think I'm hiding away a bit because of the MS and need to grit my teeth and get back out there. I still see this big MS badge on me and need to convince myself that no one else does.

Jane - MS nurse: Mary your confidence will grow as time goes on and as you become more aware of what your MS is all about and how it affects you. You will also learn very effective strategies to manage your symptoms on an everyday basis.

Kate - MS nurse: MS aside most people have some baggage or skeletons in the cupboard! We all have insecurities and worries. Everyone has positive things about them and focussing on these positives not negatives boosts your confidence. Every time you have a negative thought, try and counteract it with a positive one.

Chrish: I know (I think) there are technical ways to address erectile dysfunction (I have tried medication, including Catherject), but my wife does not feel it's 'natural' and says I should just give up. Any ideas?

Kate - MS nurse: Do you think your wife understands why your problems are happening?

Jane - MS nurse: MS can create physical and emotional barriers and relationships can suffer as a consequence. It may be in your case that counselling or communication with a healthcare professional may help along with symptomatic treatment.

Chrish: I do counselling but wife's not keen, which destroys the point somewhat. It's hard to see a longer term as MS worsens.

Jane - MS nurse: Maybe you both need to be honest with each other about what you want from your relationship.

Chrish: Thanks Jane and others. Got to go now.

Jane - MS nurse: Good luck and I hope you find the answers you are looking for.

Mary: I actually came here to talk about my mother. She seems to find every article ever printed on MS and sends it on to me. I know she needs to do something to help, but I find the stuff she sends rather depressing and overpowering. Yet I know if I asked her to stop she'd feel hurt. Any ideas anyone?

Jane - MS nurse: Even though she is only trying to help, telling her what does and doesn't help you may make things easier for both of you.

Kate - MS nurse: You're right, this is a difficult one. I think you have to say that although you're grateful for her help, you have enough info for the time being. Are there other ways in which she could help you, eg ironing - this might distract her!

Mary: My mum lives some way away and I think sending press cuttings is her substitute for nursing me night and day. I know I should be grateful that she cares and recognise that she needs to do something, but it can be overpowering and wearing to read about all manner of slightly flimsy 'cures'.

Kate - MS nurse: Do you need to read them? Does she ask you about them after? It is a constant reminder for you isn't it? Maybe direct her to more reliable sources of information such as MS Trust or MS Society.

Jane - MS nurse: She will always be your mum, Mary, and mothering you is what she does best. She probably needs to know and feel she is doing everything she can. Do you have much contact with her?

Mary: Yes, we talk often. It is just motherly behaviour. Maybe that's what gets to me. It's hard to say what I mean without sounding mean spirited.

Jane - MS nurse: Maybe letting her know on a regular basis as to how you are doing may also help her. My mum lives quite far away and just wants and likes to know that I am okay.

Kate - MS nurse: It is perhaps motherly behaviour that needs to be channelled in another direction. It's great to have her support, but it's got to be helpful support and not a stress to you. You aren't mean spirited at all - you sound like a caring daughter who knows it's only her way of trying to help.

Jane - MS nurse: It is difficult, but your mum is finding it hard too. No parent likes to see their child ill, no matter how old they are. I am sure she would not be offended if you were honest with her about how you feel.

Mary: To be honest, when I first came down here, it was recipes and stories about old school friends. Maybe I'm just more sensitive about the MS stuff. I'm sure I'd do the same had I got a daughter with MS.

Jane - MS nurse: It looks like you are both trying to do what seems to be best for each other, but it is not always necessarily the case. You sound such a lovely person and I am sure your mum is very proud of you.

Mary: Mothers and daughters eh? No pleasing either of us ;-).

Jane - MS nurse: Do try and talk to her if you can, Mary, she does need to feel included. Letting her know how best she can help you can be of benefit to both of you. Mums will do anything for their children, you just have to ask.

Anne: I recognise what Mary says. I've moved back home now I can't really look after myself all the time. My parents are my carers. With my mother it has rekindled some of the teenage spirit and we regularly have a bristly time of things. Dad doesn't say so, but I think he was looking forward to a footloose retirement and he finds himself still looking after his daughter.

Mary: I do sympathise, Anne. I'm worried that I'd be like that with my mum if I went home.

Kate - MS nurse: Hello Anne. This is a difficult situation for all of you, and even though you need some help it is important that you all have time to carry on with your own interests. It can be very difficult when you don't have a breathing space from each other. Some people find it easier to have formal paid carers than rely on parents. Have you given this any thought?

Jane - MS nurse: It can be very difficult for parents who are carers to their grown up children. It is not unusual for mums and dads to feel differently. How do you feel about your situation?

Anne: Frankly, I feel a little trapped. I rely on my parents for getting about and find I have to carve time to myself out of the day. As they took me back in when times were quite rough, I think it would be difficult to alter the situation without it seeming that I'm slighting their kindness and hospitality - even though there are these underlying problems.

Kate - MS nurse: A lot depends on how they view the situation. It may be that they would like a bit more separate time as well. Any caring situation has got to be sustainable in the long term and that includes time out for all of you. Some people are able to get community transport to get out to college/groups/shops/day centres etc. I have some people with MS who have direct payments from social services to employ a personal assistant to enable them to do things independently.

Jane - MS nurse: Have you ever discussed these issues with your parents, or have you ever had any outside help?

Anne: I'm afraid we've all got ourselves into a position where we would prefer things to be otherwise but we can't talk about the problems we present each other for fear of hurting.

Kate - MS nurse: That's difficult, Anne. So many problems arise from not being able to be frank with each other! Perhaps you could broach the subject by stressing that you are worried about them not getting enough time out, rather than admitting it's what you need!

Jane - MS nurse: Do you have access to an MS nurse at all? Your parents could still be the main carers if that is what you and they wanted, but it also means you all get time out that is so important. What would you like to change about your situation?

Anne: I think I would like some space to myself. MS has constricted my world a lot in recent years, and I've compounded this by going home. How ungrateful I sound! But here I feel like 'the daughter' not an adult with my own life.

Jane - MS nurse: It is perfectly understandable how you feel and having some space for yourself is essential. You don't sound ungrateful at all. In fact quite the opposite. But I get the impression it is getting you down. There are healthcare professionals that would only be too happy to help you all get some space.

Kate - MS nurse: No, Anne, you don't sound ungrateful. Everyone needs some kind of social life away from their nearest and dearest. It's hard having been totally independent to then have to rely once again on parents.

Anne: Maybe I need to be a bit more active in saying what I need. I came home following a bad relapse and a long period of poor health. Mum rather took control and the scene was set. After a while, how you live is how you live.

Jane - MS nurse: Is it possible for you to get a healthcare professional involved that could speak on your behalf and address the issue to suit everybody's needs?

Kate - MS nurse: If it's too difficult to have a discussion with your parents, perhaps you can start to make some enquiries about what help there is locally to get you out and about and back into social and leisure activities. Often rehabilitation teams are good at this kind of thing.

Anne: I think things are a bit sparse here (in Brecon), but something that would be 'my' time would be good.

Jane - MS nurse: Is moving out of your parents home a viable option for you?

Kate - MS nurse: You seem as if you have an active mind and need stimulation outside the home - do you get to do much at the moment?

Anne: I really need a wheelchair to get around (unless the council put sofas down all the streets that I can hang onto!). I hadn't thought of dial-a-ride or whatever until I started talking here. Maybe there's something out there for me. This chat is very helpful - it allows me to say these things. They don't seem as mountainous when told to someone else.

Jane - MS nurse: I am glad you are finding the chat helpful, Anne, but there are lots of options open to you and your parents that you are probably not aware of. Is there a healthcare professional you know of and would feel comfortable with to discuss your options.

Kate - MS nurse: I'm not sure whether you have an MS nurse in Brecon but if not, a rehab team might be available to help you get sorted. Some areas have disability resource centres which are full of helpful info / equipment etc. Social services can also give advice on these sorts of issues.

Anne: I don't think we've looked at social services because mum looks after me. In our family, social services are associated with trying and failing to find the right help for my grandmother in her declining years. I suppose I should make a friend of my GP.

Jane - MS nurse: It is well worth a visit to your GP. He/she will be able to point you in the right direction. If you didn't want to talk to somebody in person, the MS Trust or the MS Society would be delighted to help you and provide you with information to help you get out and about more, and any other queries you may have.

Kate - MS nurse: Social services can possibly supplement the help you already get, and can also do an assessment for your mum in her own right, in her role as a carer.

Bill: My wife seems OK with MS. She struggles by and tries not to let it get on top of her. She doesn't like to read or hear much about it - her way of coping is to just get on with things. I do read things and it scares me to death what might be in store. I try to be cheery and supportive but I'm worried that any little wobble is the start of a slide downhill.

Kate - MS nurse: Couples often have very different ways of dealing with MS.

Bill: I find it difficult not being able to tell people how I'm worried about the MS. Everything is geared to my wife - which is quite right, she's got the MS. But I feel I'm bottling it up and may just explode one day.

Jane - MS nurse: What you are experiencing is very common. People with MS like to get on with their lives as much as possible, concentrate on the do's as opposed to the don'ts.

Kate - MS nurse: The uncertainty about how MS will affect your wife in the long-term sounds like a worry for you. Maybe your wife's way of just getting on with it is her way of not dwelling on it too much. The trouble with trying to ignore MS is that sometimes people who do that don't always get the help they need or have symptoms that could be better managed if they asked for help. Is that the case for your wife or is she coping OK anyway?

Bill: She seems to be doing OK. Her symptoms seem quite stable and she meets up with a few other MS people occasionally. She's doing pretty well really. Meanwhile, I see what's in the books and on the web and struggle to get by.

Jane - MS nurse: Of course you worry about your wife, and the wobbles are part and parcel of everyday living. It is only natural you think the worst when they occur. People cope with things very differently. Can I ask you about your worries and what it is you fear?

Bill: I'm worried that she'll end up needing constant care - unable to walk or do much for herself. I'm a few years older than she is and I worry what will happen after I'm gone?

Kate - MS nurse: It sounds as if you need to speak to someone. I know what you mean about everything being geared up for your wife, but MS affects the whole family to some extent so you do also need some support. You might find some of the MS groups are attended by partners and it might help speaking to them. Many areas have carers support groups. A lot of information about MS can be scary but I'm sure you know that for many people it's not necessarily a disabling condition and she may never have the problems that you fear.

Bill: I lost a sister to cancer - which I know is completely different - but seeing her go downhill rapidly makes me worried - probably overly worried - for my wife.

Jane - MS nurse: Do you ever attend the MS sessions with your wife? There would be people in the same situation as yourself that perhaps you could relate to. You definitely need to talk to somebody as this is obviously a very worrying issue for you. The MS society would be able to direct you to any carer groups that are in your area.

Bill: I have never really looked for something for me. It has tended to be for her.

Simon - MS Trust: For MS Society branches see www.mssociety.org.uk or ring 020 8438 0700. There are also several groups for carers. You can find details in the Links section of the MS Trust website at www.mstrust.org.uk or ring us on 01462 476700.

Kate - MS nurse: Our previous experiences do have an effect on how we deal with difficulties. Learning to live with MS and not live in fear can be hard, some people benefit from seeing a counsellor about these sorts of issues.

Jane - MS nurse: I am sorry to hear about your sister, but your wife's MS may not get any worse. She is managing well at the moment taking one day at a time. Try to live for today and make the most of it. Do you have any access to healthcare professionals that you could talk to about your worries?

Bill: I've been wary of talking to people for fear that they would confirm what I've read. But things are getting on top of me, so I think I shall try and find somebody.

Kate - MS nurse: You may be surprised if you do speak to others. I'm sure Jane will agree, we have many people with MS who have been diagnosed for a long time and manage very well with maybe the odd wobble, but without life turning upside down.

Jane - MS nurse: Kate is so right, Bill. People want to live their lives to the full with or without the wobbles. The course of MS is very unpredictable, that also makes it hard, but you might be worrying about something that may never happen. I hope we have given you some ideas about where you can get support.

Bill: Thanks Kate and Jane. You've been a great help. Goodnight.

Jennifer: How can I stop the guilt? I suffer from pain and although I lead a near normal life as a journalist and author, at night when I am hurting I feel so useless. I don't help by always making sure my husband and daughter have everything they need. I guess I spoil them? And when I am in pain well they don't have to say anything but you can tell by the sighs etc that it is an annoyance to them!

Kate - MS nurse: Have you seen anyone about your pain? Pain is one of those 'hidden' symptoms that are so hard for others to understand. It can be difficult if you are always a capable 'do-er' to then admit you need a bit of help and understanding.

Jennifer: I am under the care of a pain specialist and I take Lyrica 600mg per day. I am afraid over time I have adjusted to all the other medications and it appears that this may also be the case with Lyrica. There are few options left as I do not want to use strong medications that may make me high/sleepy. Not with my life. I need my brain active. It's a case of put up or shut up!

Kate - MS nurse: Does your pain get worse when you are tired etc?

Jane - MS nurse: Where is your pain and when is it most uncomfortable. There are many different types of pain in MS including musculoskeletal, nerve, acute which is sharp and subacute which is pain that can last for days or longer. You may be having a combination of these, which makes it difficult to treat.

Jennifer: Knees, hips and spine. Night time is the worst. In fact, if I need to call out a doctor it is always at night. I have been checked out for other possible causes, but it is the MS nerve pain. No cure. I find that the pain is also interfering with our sex life to the point I feel its more guilt.

Kate - MS nurse: It is quite common for symptoms like pain to affect sexual relationships. After all it's hard to feel relaxed and 'in the mood' if you are in pain.

Jennifer: Hubby says not to worry, but you can tell it bothers him. I probably try too hard for normality.

Kate - MS nurse: Perhaps you need to plan your sex life around times when the pain is more manageable. It doesn't sound terribly spontaneous but at least making it a priority some of the time will ease your guilt! It does sound as if you might be overdoing it and this could be exacerbating the pain.

Jennifer: With my job and the books and my freelance work, I feel the workload is unending. I can't afford to stop as we have become used of a certain lifestyle. If I don't work, our income drops to the point we won't manage.

Kate - MS nurse: That's hard, Jennifer, but you have to weigh up your current way of life and whether its feasible to carry on in the same way. Sometimes people have to make quite big adjustments to work etc to get life on an even keel and cope better with symptoms. You aren't invincible!

Jennifer: I came up with the idea of us waking an hour earlier, but this died off after a week as my husband said he is too tired in the early morning.

Kate - MS nurse: Your idea of waking early sounds good to me. If your husband was very upset about lack of sex life I'm sure he would have taken this opportunity.

Jane - MS nurse: Even though the workload is unending, it is important you take time out to rest. Also ensuring you have good posture when you are working in a seated position can also help.

Jennifer: This is half my problem. All my life I have worked and worked hard. Before MS, I managed the house, my full time job and freelance work. Now it seems impossible to carry on. I can't see my daughter giving up her things or my husband getting a smaller car, so I have to work.

Kate - MS nurse: Jennifer are you getting the correct benefits? If not then this might allow you to do a bit less work.

Jennifer: I don't claim benefits as we are both in fulltime employment.

Kate - MS nurse: You may be eligible for disability living allowance - its not means tested. The MS Society do a good booklet on claiming DLA. (MS Essentials 13: Claiming Disability Living Allowance – ring the MS Society on 020 8438 0700)

Jennifer: I was offered a pump for my spinal spasm but I feel I am too young for this yet. I am slightly disabled and use a stick. Otherwise I am fine, without the pain. I have had no relief now for two weeks and it's killing me. I give in at times and take morphine but only at night.

Jane - MS nurse: Does the morphine help?

Jane - MS nurse: Spinal pumps can be very effective, and if that is what the pain clinic advised, it may well be the right option for you to get on top of your pain.

Jennifer: Morphine does get rid of the pain and I don't get high, thank God, but I hate taking it for fear of dependency.

Jane - MS nurse: Maybe it is time to talk about things with the family. If you are continuously doing everything for everyone, they are not going to know there is a problem.

Kate - MS nurse: It sounds as though your current lifestyle isn't giving you quality of life. Perhaps your family wouldn't mind about the material things if you had more energy to spend with them?

Jennifer: I have tried! My husband kept leaving the car catalogue around the house until we bought the stupid thing. My daughter is young and caring but she loves her dance, swimming, football, art etc. I wish sometimes that I worked in a lesser job then so many would not be depending on me.

Jane - MS nurse: The situation you are in is difficult, but your pain sounds excruciating and you can't go on like this. Something has to give and you may need to compromise, making your family more aware of what it is you are experiencing is a good place to start.

Jennifer: MS is one hell of a disease - so diverse and incurable. I am living but I need the pain to go.

Jane - MS nurse: Do you have a follow up appointment at the pain clinic?

Jennifer: Yes, I go monthly. He wants me to take MST [morphine sulphate, a slow release variant of Morphine]. If I take morphine every day will I become an addict?

Kate - MS nurse: When people use opiate medication for pain then no, they don't become addicted.

Jennifer: I know the time is coming to give in and take the pills. I just worry I may be zonked.

Jane - MS nurse: MST can be very effective for pain but like any other medication it needs monitoring. It is also one of those drugs that gets increased over time.

Kate - MS nurse: It sounds as if you have had your pain for a long time and been through a lot of treatments. There's unlikely to be a quick solution to this problem but adjusting your lifestyle to make it more manageable is half of the answer.

Jennifer: I know this it is fear of failing or letting people down that is preventing me from acting.

Jane - MS nurse: Your lifestyle has a big role to play here in conjunction with medication. Tablets alone will not resolve the issue.

Kate - MS nurse: It would be you taking some control and sorting your situation out, rather than your pain controlling your life.

Jennifer: You are speaking to the converted. I just need the strength to change things. I see the time is 7pm. I don't want to hold you up. Thank you for listening.

Kate - MS nurse: Sorry if we seem to have been nagging you - but we do see this a lot when people feel that there is no other way of life and trying to soldier on as they always have.

Jane - MS nurse: It could be quite the contrary. If your pain is more controlled, you will feel more in control and may get more out of your life that way. Do take the advice of the pain clinic. Good luck, Jennifer.

Kate - MS nurse: Hope things get a bit easier for you Jennifer. Goodnight.

Simon - MS Trust: We've come to the end of our time. Thanks to Jane and Kate, and to Kerry and Julia earlier in the day. And thanks to everyone for their questions and comments and being so honest about the effect of MS on their families.