

Partners and MS

Chatroom

30 April 2009

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30 April 2009 - 10am to 7pm

- **Lisa Black** - *MS nurse*
 - **Jo Johnson** - *neuropsychologist*
 - **Lynda Hind** - *neurology nurse*
 - **Julia Segal** - *MS specialist counsellor*
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This chatroom is an open forum and so the views expressed by participants are their own and are not necessarily those of the MS Trust.

A list of publications and resources mentioned during the chatroom is at the end of the transcript

For further information on topics raised, please contact the MS Trust Information Service on 01462 476700 or infoteam@mstrust.org.uk

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Simon - MS Trust: Welcome to the chatroom for the partners of people with MS

Jacqueline: My husband was diagnosed with MS two years ago but is still really struggling to come to terms with it. I feel that we could both cope with his symptoms if he would just be sensible, accept what he has and begin to work out the best way to overcome the problems.

He has started setting himself silly targets, for example "I'm going to walk to the end of the road today." The road is two miles and he would never have walked this before his diagnosis, so why does he want to do it now? He will then set off and I'll have to go and literally lift him off the roadside and bring him home in the car and he will be in a foul mood for the rest of the day. Or he will take the stairs instead of the lift. Why does he set himself these unrealistic challenges? Does he do it to prove that can't do it?

He is self employed doing a very physical job - again he is keeping taking on more work than ever before. Then when he can't do it and lets customers down he gets very depressed.

The occupational therapist helped me get a room converted to a wet room with a shower, but he still insists on going to the bath and I have to lift him out each time.

Is this behaviour normal?

We have five children - from 10 years down to three months - which is a handful - but I now feel like a single mum to six kids including him. Going back to setting challenges - I'm sure we only had our last baby because the MS nurse told him it wouldn't be sensible!

Another question I have is about alcohol - are there any recommendations when it comes to alcohol and MS? My husband has quite a big circle of friends and every weekend they would meet up to watch football and have a drink. This past year he has only been able to drink a couple of drinks before falling over or losing control of his bladder. He obviously doesn't want to miss out on his social life with his mates - which I understand - but why won't he just go out and not drink? It's not fair on his friends to have to carry him to a car and back home, or help him go to the toilet. I feel that soon he will start to lose friends. When I brought the subject up with the MS nurse she just said that he needed to continue to enjoy life and the odd drink didn't do any harm - so now when I get on at him he reminds me that the nurse said it was fine.

I began to think he was alcohol dependant - but surely two drinks a week doesn't make him an alcoholic?

I've tried inviting people round to ours but that's worse as he thinks he can drink more and his friends then have to watch me lift him to his bed or change his clothes.

When I speak to him about this or any of the other issues he just makes me feel really sorry for him and guilty.

I do sympathise with him but we are now two years down the line and I'm getting really frustrated. When is it going to sink in that he has MS and he isn't going to

get better over night? I don't want him to lock himself indoors and just lie down to it, but he needs to start making adjustments.

I'm sorry to ask so many questions - I just don't know where to turn for help.

HelIMS: Everything is so sad in these chatrooms. I'm glad it's not up to me to answer Jacqueline's question. Life sucks when you get MS but give the partners a damn break they are suffering too. What can I say, I don't know. Your husband needs to see that this is a huge problem with five children to look after as well. I'd shout help! I wish you all the best.

Lisa - MS nurse: It sounds as if you feel very alone and have so many problems to address. Everyone acts very differently to their diagnosis but setting unrealistic goals is setting oneself up for failure. So many emotional and thinking problems can be part of MS and it is the physical problems that are easier to understand. Could you arrange a session with your MS nurse to both sit down and attack one problem at a time?

Also have you looked into more help, maybe through direct payments or do you have a welfare support officer through an MS Society branch? The difficulty is that MS affects all the family, not just the person with it. Hang in there. It is early days and people to come to terms with it and situations then can change.

Jo - neuropsychologist: I am so sorry that you are having such a tough time. In my opinion it is often as tough for a partner as the person with MS. It is always hard to give advice without knowing someone but I wonder if he has some cognitive problems. Sometimes this can make people deny the real situation and behave in a way that does not seem sensible. Otherwise it may just be that denial and pretending everything is normal is his way of coping. I wonder if your MS nurse could refer him to see a psychologist to chat about how he is feeling. Would he accept that sort of help?

Jeff: It sounds similar to my wife - denying to herself what she can't achieve and fighting MS by carrying on regardless. In supporting her I find I'm wearing myself down

Jo - neuropsychologist: It is important to look after yourself too. Find some people to chat to as well as seeking hobbies or activities to get you out of the house and mixing with others.

Lisa - MS nurse: As regards alcohol, there are no strict guidelines, but it does obviously make mood, emotions and balance worse. It also depends on what medication he is taking.

Jacqueline: The MS nurse is very matter of fact with him and he faints every time he sees her. He never does this at any other time - it's as though he shuts down just to avoid talking to her. He gets on well with his GP but I've spoken to her and she says that unless he makes an appointment and discusses it with her, she can't help. She did put him on anti-depressants very early on but although I keep collecting his repeat prescriptions, he hasn't been taking the tablets. He tells me he is but I'm not daft and have been counting the pills! I used the cognition chatroom on Tuesday as I feel he has memory problems but again he doesn't seem to think there is a problem.

ChrisMac: Jacqueline, I was diagnosed two years ago too. It's really hard to accept the changes you need to make and to accept your limitations. I am lucky to have a fabulous MS nurse who told me I need to work with it, not against it. I

still don't like the limitations it places on me, but life is just a bit sucky at times. Until your husband can accept that he can't fight it but has to work with it, he'll keep on and it's self-defeating. But he has to make the decision for himself. Having MS strips you of so much of your independence that making your own choices where you can becomes even more important. Good luck, but don't give up on him. Support of your loved ones is the most important thing.

Jo - neuropsychologist: It is very hard to cope with it all when your partner seems to be making things worse rather than helping himself. Have you had any time with the MS nurse by yourself? It may be worth asking for an individual appointment so you can talk without feeling worried about upsetting your partner. Perhaps she can help you come up with a plan about how to tackle some of the problems.

Jacqueline: Thanks for that, I will give her a call and see if she will see me on my own - I'm not sure how it would go, I'd feel really guilty 'going behind his back'.

Jo - neuropsychologist: Don't feel guilty. You need an opportunity to talk about how it is for you. Think about this as the best option for helping him at the moment. It will also be helpful for the nurse to understand what is going on as professionals can only know what they are told by the person and if that is inaccurate, she can't help you as a family.

Lisa - MS nurse: I think what Chris said is very helpful and Jacqueline you should not feel guilty. Coping with five children is hard enough. I have had the same difficulty engaging with people but if you keep approaching it things do change. Maybe the MS nurse can support your coping if your husband won't engage. Anti-depressants can be so helpful as it is not just about the situation from outside it is about what is happening inside.

Chloe: Hi, Jacqueline, I'm so sorry to hear your situation. Perhaps your husband has previously seen himself as head of the family and in control, by not admitting to MS he allows himself to believe that nothing has changed so that he can retain that belief. You say that it is like having six children, well perhaps instead of worrying yourself into an early grave, you could step back a little as we have to with our children at some point in their lives and stop protecting him. I think perhaps this may allow him to find a way of living with MS in his own way, rather than continually 'fighting' you. This will also give you some breathing space to take care of yourself. I wish you well and would maybe suggest that you find yourself a counsellor to whom you can off load in a confidential environment. When someone in the family has something like MS, contact with professionals can sometime feel very public! Hooray for chatrooms eh?

Jeff: Guilt was a big thing - you know, she is the one with MS, what have I got to worry about? It makes you feel so trapped at times

Jacqueline: Hi Jeff, where do you turn to for help? Do you feel the same as me and feel guilty for addressing your own problems when your partner is the one with medical condition?

Jeff: I'm lucky to have a friend I can let off steam to. He buys me a pint, I blurt out my frustrations, he buys another pint, some kind of equilibrium is restored. It would be a nightmare without this.

Jacqueline: That sounds good - maybe I need to let off steam to someone instead of putting on a brave front.

Does anyone know if there is a support system in place anywhere for partners of MS sufferers?

Jo - neuropsychologist: You are right. It is so important to talk about how you are feeling. Lisa and I started a group for male partners for this reason and it has become very well attended. Frequently partners feel left out and are left to struggle alone with all their negative feelings which are very reasonable given MS impacts the whole family.

Simon - MS Trust: The next issue of our Open Door newsletter will have an article from one of the people involved in Jo and Lisa's group. This will be published in May

Jo - neuropsychologist: Yes, brave fronts usually crumble eventually and then you are not in a position to support your partner. It is important to try and get help before you feel in crisis as it is then more difficult for everyone to recover. In a lot of areas they have a carers' liaison service that offer counselling and practical support. You could ask you MS nurse if she could help you set up a partner or men's group.

Lisa - MS nurse: Often the local MS Society branch has a relatives group or a named contact in a similar situation. Sometimes safety in numbers and sharing experience can be very helpful.

Jeff: It's a mixture of brave front and steam-letting. The one needs the other. I just hope I'm doing the right thing for my wife

Jo - neuropsychologist: Getting support for yourself is always the right thing to do. If you feel well supported you will be a much better support to her.

Lisa - MS nurse: I am sure you are doing your best. There is no guide to follow, and it is a hard situation you are all in. It's using the tools you have to get through the best you can - but just coming and using this forum shows how much you care!

Jeff: I sometimes wonder if I'm shielding her in some way. I feel she is in denial about MS to some degree and I'm reinforcing rather than challenging this. It tears you up to think you're doing the wrong thing

Lisa - MS nurse: People cope in very different ways and denial can be a coping mechanism. Coping can change all the time and your wife may be in a different place in the future and that may make it easier for you.

ChrisMac: I was diagnosed aged 45, (despite being the 'wrong' age and gender - male). I started a new relationship coincidentally at the same time, which I thought was great as it meant she had her eyes open. But it's been far from plain sailing and has now broken down, probably irretrievably. I know all the things about the person being more important than any disability, but now I'm in a position where I want a relationship, but I don't know how to find someone who is truly accepting of me. My partner was very kind and supportive, but it's a tough gig. Can I hope to find someone who will be that special and be able to deal with it all, or am I living in cloud cuckoo land? Ironically, my ex-wife has

been fabulous - but this may be helped by not having to live with me! I don't want pity, or someone who feels that I am a 'project'. Just someone who wants me for me.

Jo - neuropsychologist: It is so tough when a relationship breaks down. Try not to presume it was totally to do with the MS as it sounds like she was fully aware of your diagnosis. You need to give yourself time to get over this relationship properly and resist the temptation to rush into another too quickly or the next relationship is more likely to fail. It sounds like you have lots of strengths and you may need to spend the next few months building your self esteem by mixing with supportive friends and taking up new hobbies. If you feel happier with yourself, someone else will come along who can see how well adjusted you are and want to invest in you despite your weaknesses.

Lisa - MS nurse: I don't think you are living in cloud cuckoo land. Have faith, there are some fabulous people around who I have met on my travels as an MS nurse. Many found partnerships after diagnosis. And maybe it is the same for people without MS - we all have to kiss a few frogs before we find a prince!

Bella: I am at the beginning of partnering an MS chap. He is wasting away before my eyes muscle wise and not a sniff of physiotherapy advice or massage. I am keen for lots to happen but he tells me it's his disease and he will wait for the professionals to give him the go ahead with things! There is definitely a need out there for a support system for partners. A punch bag in the shed would be good too. I find deep breathing and counting to 10 helps, but often find myself in the loo trying not to cry at the ghastliness of the MS.

Jo - neuropsychologist: This sounds frustrating for you and you must feel helpless. I guess it is important to feel in control of things and he may not want you to get involved with his healthcare. However, you might want to gently ask him about the length of the waiting list for physiotherapy and support him to make some calls as to when he is likely to be seen. There are lots of private neurophysiotherapists and some people find it helpful to pay for a private assessment during the wait for NHS services. Of course, this is not good enough but in reality people often do not get what they need. You can make sure you find out what local services are in our area so he can contact people if he wants too.

Jeff: Bella, it's really difficult, isn't it, when you want to charge in and start getting things moving, and they don't want that. You feel so frustrated and impotent

Jo - neuropsychologist: Sometimes that is how people cope by feeling that they are in control of just one area of their life even if it looks to others like this is not a very sensible approach.

Lisa - MS nurse: Hi Bella, everyone with MS should have access to physiotherapy. In my area we have a great neuro-rehab team but this is not the same everywhere. Sometimes the waiting lists can be long. The MS centres can have seated exercise classes and they can be a great source of support, as are specially adapted gyms that sometimes are situated in day centres. You don't need to use the day centre but the physiotherapist could devise an exercise programme to do there. There is also a great book that is free from the MS Trust with exercises in, and not forgetting the Mr Motivator DVD if you can stand the lycra!

Simon - MS Trust: The book of exercises is [Exercises for people with MS](#). As Lisa says, there is also a DVD called [Move it for MS](#).

Lisa mentioned the MS Therapy Centres. These are local charities offering a range on non drug treatments for people with MS and many of them provide physiotherapy at a subsidised rate. You can find a map of them on our [Map of MS services](#)

Debz: My partner has had MS (now secondary progressive) since 1994 but is deteriorating. He stays in bed most of the day and has lost interest in doing anything now. He is totally reliant on me for all his personal day to day care and I'm worried about the future. I just saw the comment about neurophysiotherapy. We are paying £65 a session for one to visit us at home

Lisa - MS nurse: I was quoted fifty pounds a session. It is very expensive. Hopefully everyone knows about disability living allowance - not for physiotherapy but for living with the disease.

Jo - neuropsychologist: Debz, how sad for you. Do you feel you are being well supported? Has someone made an assessment about whether he is depressed and needs treatment for that? Otherwise, he may be experiencing a lack of motivation due to cognitive changes, does he seem happy to live like this. If so it is often then you who will need to get plenty of support and respite to cope.

Debz: We get all the benefits as well as direct payments but most our money goes on carers and large utility bills!

Lisa - MS nurse: Would you like more help? And do you know where to go to access it?

Debz: He says that he is so tired that it doesn't bother him but I'm afraid on occasion I get short tempered. I never have a full night's sleep as I have to turn him every hour or so and also there is the loo visits. Between you and me, I would love him to have some respite so I can go and see my parents who live about 400 miles away but he wouldn't entertain that idea and we only have a one bedroom flat so someone staying over isn't an option.

Lisa - MS nurse: If you already have social services input you may be entitled to independent living fund for more help. They would not fund physiotherapy but you could ask for a support worker who could be taught exercises by a physio and continue this. Ask your social worker or look at independent living fund online.

Debz: That's a good idea. I know I must sound so mean but I just get so worn out. Recently I was ill and still had to carry on as 'normal' as no-one would help and it's left me feeling very drained

Lisa - MS nurse: To maintain this situation you need a break, otherwise the whole situation could breakdown. Would your husband consider respite outside the home?

Jo - neuropsychologist: Is he able to think about your needs? If he can, you may need to tell him more clearly how stressed you feel and that if you do not get some respite you may not be able to keep caring for him. Can you talk to your MS nurse about other options? Would he be able to stay with a friend just

for a couple of days or are his nursing needs too great? If so, there may be an option for him to stay at home and to have the district nurses/support workers to come in every couple of hours to get his meals and do the nursing tasks. It is vital you find a way to get a break!

Debz: No, I just try and take time out when he's settled. I'm afraid I'm starting to feel resentment. He needs total help with all his care. I even do his catheters as he can no longer use his hands properly. We have hoists in the bedroom and bathroom

Jo - neuropsychologist: It is very normal to feel resentment when you have no life of your own. It is really important you talk to social services or your MS nurse about how you are feeling and find a way to get some respite. If you go under physically or mentally, that will not help him.

Debz: I'm sorry for rambling on but I find it hard to talk verbally about how I feel and if I am on the phone he can hear what I am saying. He already feels bad enough about everything without me making him feel any worse. Thank you for your advice - it really does feel better just talking to someone who understands. I will try and get some more help

Jo - neuropsychologist: You are not rambling, you are saying what so many other people feel - very alone and struggling to cope with what is often an impossible task. Do you have a professional who you feel able to ask for some practical help?

Lisa - MS nurse: Don't feel you have to put up with it all. Talk with the MS nurse and social worker about a review of care. You are not being selfish, you are being proactive. And every one needs a break. You are not super human and you must think of your own needs. It will make the situation easier to cope with in the long term.

Frank: This sounds rather selfish, but I sometimes feel like a bit player in my wife's life. Everyone is very concerned about her and her health and I find myself feeling pushed out of the limelight. It used to be her and me - now it's her, her MS and then me (this does sound very whiny). Does anyone else feel like that?

Lisa - MS nurse: Hi Frank, it does not sound whiny, just realistic. I think it is just as hard for the partner and makes me more aware of the effects through the family. It is good to talk through the difficulties. Who would you off load to?

Frank: I'm wary of talking this through with our friends, as I think they'd think badly of me. She has a long-term condition and needs drugs and treatment, whilst I sound like I'm bothered by not getting enough attention. I think she's coping with the idea of MS better than I am

Jo - neuropsychologist: Life for partners is really not easy. When a diagnosis of MS is given, a lot of the help and information is aimed at the person with MS. This can make feel partners excluded and I think it is reasonable to feel left out. I think family and friends can also often forget that MS impacts the whole family. Partners often have to cope with their role and take on all the things a partner used to do. This is exhausting both mentally and physically. The loss that occurs is hard to cope with. Partners often lose a lot of social contacts and may even have to give up work. This leads to feelings that are a bit like grief, sadness, tearfulness, anger and guilt. Talking helps but if you feel you are depressed you

should see your GP and ask to talk about the options for treatment both medication and psychological support.

It is not selfish to have feelings and it is really important to find people who you can talk to. Sometimes it is easier to talk to people who are struggling with the same issues. Do you know other people with MS? If your friends are really good friends they would want you to talk to them and may also be able to offer some practical support. It is harder for men as they are generally less comfortable with talking about their struggles and their male friends find it less easy to ask and support.

Jacqueline: I feel a lot better realising today that I'm not the only one in this position - I wonder if there isn't a permanent chatroom somewhere out there where we can all offload our feelings without feeling guilty or whiny? I find it difficult talking to friends or other family as they have their own problems too.

Lisa - MS nurse: The MS Society has chatrooms for this purpose and there is a new website for younger people with MS called shift.ms, which looked great.

Jacqueline: I logged on to shift.ms yesterday after seeing it mentioned on This Morning - it looks really good and very positive rather than gloomy. They should have a bit for partners though as I'd feel wrong using up their time when MS sufferers could be using the space. I might email that to them as a suggestion.

Frank: My wife has decided not to join the MS group. She doesn't want to feel she's part of a 'club' and would rather just keep the MS for the doctors and nurses. Other than in the occasional waiting room, I rarely see people with MS.

Jo - neuropsychologist: That does not mean you can't join the MS group. Lots of people attend without their partners. There are sometimes local groups for male carers as well, ask at your GP surgery or the MS nurse should know.

Simon - MS Trust: The links Lisa mentioned are:

- MS Society discussion lists
- shift.ms

There are several other groups, some of which have partners as well as people with MS, for instance

- Jooly's Joint
- MS People
- MS People UK discussion list

Alternatively, there are our Facebook, Twitter, etc groups.

You can find the links to all of these groups at the end of the transcript

Lisa - MS nurse: I think a lot of people decide not to join local groups but it is good to know they are there if you need them. Depends what is on offer. Most local groups are run by the MS Society but some MS nurses run information groups or fatigue management groups that are less about social stuff more about info. Everyone copes differently. There is a big need to support partners. The carers' liaison in our area offers a lot. As well as information groups there is a confidential telephone support line but this is a general carers' service not particular to MS.

Simon - MS Trust: The MS Trust website also has a page called [I am a partner of someone with MS](#). This tries to bring together items from around our site that may be of interest. This currently includes an article written by Jo about the group she and Lisa run on the south coast for partners. Maybe the idea will be taken up elsewhere around the country.

Jacqueline: The article of This Morning also mentioned Low Dose Naltrexone. There had been a conference about it and its ability to help with MS in Glasgow last week. Does anyone know if this is for use as an alternative to other medication or alongside it? My husband is on Copaxone.

Lisa - MS nurse: Low dose naltrexone is not licensed for MS and mostly brought privately. It's about £30 pounds a month I think. A few of my patients take it. It's not advisable with Betaferon, Rebif and Avonex but I do have a patient on Copaxone who takes it. Haven't seen any great success stories in my area yet.

Simon - MS Trust: We have a [factsheet on LDN](#)

Jacqueline: Simon, thanks for that - I will go and have a read.

Dave: My wife was diagnosed with primary progressive MS 18 months ago and she came to terms with it a lot better than me. She has had two courses of steroids since she was diagnosed, the second being 11 months ago. Her walking has got continually worse and she suffers a lot with migraine-type headaches, for which she takes co-codamol. I try to help as much as I can, but sometimes I feel totally useless. Is there any other medication that be given to help in any way?

Lisa - MS nurse: Yes, there is a lot of symptom control medication. As regards pain, this may be neurological pain that is often controlled by medication for other problems. For example, amitriptyline is an antidepressant but used in smaller doses say 10mg can be very useful to treat nerve pain which is what the headache may be. Best to discuss with your GP and MS specialist.

Dave: My wife takes co-codamol for frequent headaches and there is something she takes that is wafer-like for migraine headaches. But if she doesn't take these as soon as she feels it coming on, they are of little or no use.

Lisa - MS nurse: There are several publications by the MS charities on pain and MS. They are easy to read and understand and are free from the MS Trust and MS Society. There are many medications that help with nerve pain.

Dave: I wish we could all find a miracle cure for our partners! Frank/Jacqueline I feel we are all in the same boat and it does help listening to someone in a similar situation.

Jacqueline: I find it really frustrating as every month there seems to be mention of some new drug or a breakthrough in stem cell treatment in the newspapers. There seems to be so many trials ongoing at the minute and we all hope that one will provide the 'miracle cure' we are looking for.

Jo - neuropsychologist: I think we all wish there could be a miracle cure for your partners and everyone else with MS. There seems to be more research than ever before and there have been lots of encouraging developments in treatments for the symptoms of MS.

Partners often feel helpless, especially men who generally like to 'fix' problems - and MS is not fixable as yet. It does help to talk about these feelings and realise most people feel the same.

Frank: That's the press, isn't it? They only see things as 'miracle cures' or treat early research as the next great breakthrough. After so many dashed hopes we approach these health stories rather cautiously now

Jo - neuropsychologist: I think that is a sensible approach. It is hard when the media markets things as the next miracle cure, especially when friends think they are helpful by cutting out the article for you! However, there are some promising developments for the next few years.

Lisa - MS nurse: Lots of medications are for symptom control, not cures but we can do a lot about the symptoms and modify the disease. Sharing all these pent up worries and thoughts can be so helpful. All the men that come to the group Jo and I run came with great reluctance but the ongoing support I think is much needed.

Simon - MS Trust: Lisa, Jo - for people who haven't read about your group for partners, do you want to explain what it is?

Jo - neuropsychologist: The men's group started as there seemed to be lots of male partners seeking support for feelings of low mood and distress due to their partner's MS. We started with a one off meeting to think about what problems people felt most and to then think about what might help. Eight men came to the first group and all wanted to meet again. I think we now have about 25 members. We meet at a local hotel funded by one of the drug companies. They are all ordinary men who perhaps would not have thought they would go to a group but say they find it helpful. It is not a psychotherapy group and we talk about all sorts of things, not just MS. I think the most useful thing is feeling less alone.

Lisa - MS nurse: Our group has been running for a couple of years. We met bi-monthly at a local hotel we have around 15 or so men attending each time. All have wives with MS though with a wide range of symptoms and disabilities. We aim to provide support and information. It is a great group and the men try so hard to cope with all the difficulties. I admire them.

Frank: Are there groups like this all around the country or is yours the first one?

Lisa - MS nurse: Well I think we are unique! But it shows a need and is not that hard to replicate through the country. It comes down to time and money. Our group is funded by a drug company donation to a charity fund, but local groups within the MS Society have carers groups. Maybe talk with your MS nurse about the possibility of starting a group in your area. Although I could not do my group without Jo's support and input, the MS Society also make a contribution as it is a bit diverse.

Jo - neuropsychologist: I have not heard of others and we are going to present it as a poster at the MS Frontiers conference next month. The reason for doing

this is to perhaps inspire other professionals to do something similar. I think there are a lot of relatives groups around but they are often dominated by women, which can put off younger men particularly. The MS Society groups are often for both partner and person with MS. It is not always easy to admit to negative feelings in front of your partner for fear of upsetting them.

Sarah: Hi all, just been reading all this and it's brought tears to my eyes - especially Jacqueline. Thanks for opening up! I feel very much the same as you. My husband was diagnosed not long after we met. Five years on and he has not accepted it nor has he told anyone. This is driving me mad. I try to help him without him knowing so that he doesn't feel bad. Also I have told my parents and best friends 'behind his back' as I couldn't go on without talking to someone and I feel so very very bad at this. I don't know how to take this forward. He adapts his behaviour to cover up the MS to everyone and as a consequence our lives are getting more insular so that no one spots there is anything wrong. We have a six month old son and I am back at work and struggling a bit. I struggle myself with local support groups as it seems focused around the people who have worse disability and my problems seem very minor compared with others.

Jo - neuropsychologist: It often feels harder if your partner is less obviously disabled as it is easy for others to not think about how MS impacts you. It is so hard when you are younger and having to cope with work and children and your partner can't do half the work as he would without the MS. Your MS nurse may know of other younger women with children who are in the same position. It does really help to be able to talk to someone who really understands. I know of two women who met through an information day and they meet up regularly with their children and sometimes husbands too. It is a great support.

Jacqueline: Hi Sarah - I've had to do exactly the same thing - tell friends and family behind his back. We also make excuses not to attend things to avoid problems occurring. I really hope it's just a stage we are going through and he will start to open up and get to grips with things, although at the moment I don't see any 'light at the end of the tunnel'

Jessie: I don't have a partner with MS, but have a number of friends who have it. I was reading this to see if I could learn how to help my friends. I hope you won't mind me commenting. Sarah, your problems do not seem minor to me at all and I am sure they don't to your friends. Have you talked to your husband's MS nurse about your feelings? Maybe she/he could help you meet other partners facing the same issues?

Jacqueline: How do you cope with your husband and the baby situation? Our youngest is four months old and I'm scared to leave him with her for a second in case he drops her or has a wobble. But I don't want to hurt his feelings.

Sarah: Thanks guys. I hate that you're in the same boat as me, Jacqueline, but it's good to know I'm not an island! Maybe I should talk to the MS nurse.

I think bottom line is that if he doesn't tell anyone, it isn't real - even though he's injecting Rebif and can't walk down the stairs properly. Men are indeed from Mars. It's hard to understand his view when I would be weeping (and laughing) over lots of wine with my girl friends.

Do you ever have the stress that someone will say something and it will become obvious you've told them? Should we start a support group for women who have partners with MS who are in denial (I think there's probably a fair few)

Jo - neuropsychologist: I think there is a danger that you can become increasingly isolated if you go along with your partner's desire to avoid people. I think it is important to try and resist this. You need support and although it is hard and you may feel guilty, try and accept social invitations but say you doubt your husband can come due to his health. If appropriate invite a friend so you don't feel left out if it is a couples event. It is also important to try and keep up with leisure activities on your own. You may need to ask your MS nurse to arrange cover if your partner can't be left alone. If you don't socialise you will become depressed and that will not be good for you or your partner.

Jo - neuropsychologist: It is a great idea to start partners groups for men, women or both. Just talking helps but you can also hear tips for coping that you might not have thought of. Talk to your MS nurse about setting up something. You could do a leaflet and get her to give it to people she thought might be able to work in a group.

Jacqueline: I think the support group sounds like a great idea! I'm glad I'm not the only one with a husband acting the way he does! Why do they think that no one realises something's wrong. I find most people assume he's drunk. This doesn't seem to bother my husband whereas if I were in that position, I would rather people knew there was something medically wrong with me than assume it was my own fault.

Sarah: Same here! I had the police around as someone had reported him getting into his car 'drunk' outside an off-license.....

Let's think about the support group and how we could do this.

Jacqueline: I wonder if Simon would let us email the MS trust with our email addresses and we could get in touch that way after today - might help us both to compare notes.

Sarah: Sorry I've got to go as I'm at work but if anyone wants to track me down I am Sarah Lundy on Facebook with a picture of a baby in a door bouncer as my profile picture. Just put MS in your friend message. Thanks guys.

Simon - MS Trust: Jacqueline, that would be fine - email me and I'll put you in touch. The response to the men's group article in Open Door has been very positive - if someone would like to write about the female perspective of life with a partner who's in denial or 'getting by', we'd be happy to consider it for a future issue. Contact us at info@mstrust.org.uk

Jo - neuropsychologist: Good luck, might be good to try and get your MS nurse to put you in touch with local partners too.

Jacqueline: I need to go and collect kids from school but will log on again later in the day. Meantime thanks to you all for your advice and help - it has been great and I definitely feel in a far better frame of mind knowing I'm not on my own.

Lisa - MS nurse: It feels that communicating with supportive people is key. Otherwise it must be so lonely. I see a wife whose husband has MS and he does

not want to see me so I see her for support. It's not as good as seeing them together but OK for now.

Jo - neuropsychologist: The key message is that in order to survive you must get good support for yourself. Socialise with people who are supportive and be honest when people ask what they can do to help. Ask them to cook an extra meal for the freezer, do some ironing, babysit etc. Friends often want to help but don't know how and are pleased if people can tell them what to do. Take up some new activities that will build your confidence and give you new opportunities. Remember you can't be a supportive partner if you are unsupported and resentful.

Lisa - MS nurse: Good advice Jo. Can you bring my dinner round tonight?

Cat: Hi all. I'm at work so won't be able to stay in the chatroom for long but I just wanted to share a really positive experience that I had with my partner who has MS. He's called Steve and is luckily responding well to his drug treatment. He has good and bad days and mostly fatigue and tingling are the things that bother him on a daily basis, although I'm very aware of his ongoing fear for the future. Anyway, Steve wanted to do something life-changing so last year we decided to climb Mount Kilimanjaro together. It was the hardest thing I have ever done in my life and certainly was for Steve. We trained hard, getting in as much walking as possible to prepare us for the climb and then we got there and set off with a goal of getting as far as we could. Of course, the ultimate aim was to reach the summit but as the days went on, we slowly realised that neither of us was going to make it to the top. Steve, because of his MS was struggling, and I because of altitude sickness and exhaustion knew I couldn't make it to the top. Anyway, we got 90% of the way there - got to the summit camp and supported the others in our group who were strong enough to continue. I can't tell you how proud I was to see Steve's determination and how heart-breaking it was when we had to stop. He was so frustrated because he knew that had he not had his MS symptoms he would have been able to finish, but his personal strength and attitude was so amazing to witness. The whole group understood how difficult it had been for him and were spurred on by his strength. Steve runs one of the busiest pubs in Britain, regularly works more than 45 hours a week and never says no to any challenge. He is a real inspiration to me and I hope he can inspire other people affected by MS that you can climb mountains and achieve things despite what life throws at you. We're expecting our first baby in September - that will be the biggest challenge yet!!!!

Jo - neuropsychologist: Cat, it is lovely to hear when things are going well. Well done to you both!

Jim: Resentment is something I'm wary of, but I think I'm drifting towards it. With my wife unable to work and much more limited around the house, I find myself taking on more and more, as well as being the breadwinner. Not care stuff, so much as running the house. I'm not resentful of her - it's hardly her fault - but I have so little time for myself and our frustration with MS keeps bursting out as arguments between ourselves. Friends joke about women doing this all the time and seem to dismiss my concerns as just being 'a man'. It really does get me down and is ruining our relationship

Lisa - MS nurse: Are there any tasks you can have help with or use DLA monies if you receive it to help fund? Or look how your wife can do the tasks eg shop online to save you doing the shopping? Maybe looking at all you are doing would be helpful. Keep talking rather than it all coming out in an argument.

Jo - neuropsychologist: This is very common. It is important that you ask for more help. Do you have a social worker as you may be entitled to get some money for help in the house etc? If not, ask your MS nurse to think about more help for you. Make sure you allocate time for yourself and stick to it even if it means the house staying a mess or getting chips from the shop for tea. Do you or your wife have friends who could help a bit more with the practical stuff so you and your wife could have more quality time together? Also an occupational therapist might be able to work with your wife to make chores easier and manage fatigue, etc.

Jim: As I've been doing these things and I don't have MS, we haven't asked. Are there things for people who are looking after someone with MS?

Jo - neuropsychologist: You are entitled to an assessment from a social worker and that will include a carer's assessment which looks at your needs too. What you get will depend on your financial situation. Get your MS nurse or GP to refer you to social services.

Jim: As I work and don't have MS, I was under the impression (wrongly it seems) it wasn't worth asking. We're not hard up for money so much as for time and breathing space

Jo - neuropsychologist: It is worth getting an assessment. If you are not too badly off, you may want to think about paying for a cleaner for a few hours a week which would give you more time and breathing space.

Jim: Thanks Jo, this is helpful

Jo - neuropsychologist: You are very welcome, best wishes with it. Don't be fobbed off. You are entitled to help and if you are no longer able to cope, that will be awful for you and your wife.

Dave: This is really touching. I feel I am not alone. I find myself doing more and more, without complaining, and seeing the woman I've been with for close to thirty years deteriorate month by month before my eyes! She still tries to do a lot but after she does, she is drained for the rest of the day and is constantly tired.

Jim: I can recognise that. Sometimes the anger at the MS comes out as if aimed at the person with MS. Sometimes it comes out aimed at myself.

Lisa - MS nurse: Look at the tasks in a different way. Just having help with some could make a big difference. Don't suffer in silence.

Jo - neuropsychologist: It is so hard watching someone you love deteriorate but it also physically and mentally tough for you too. She might benefit from having some support from an occupational therapist to manage her time and life so that fatigue is less of a problem.

Lisa - MS nurse: There are also various medications that can help with fatigue. For instance, modafinil can help with daytime sleepiness. It is a hard task, I admire everyone's strength.

Julia - MS counsellor: Watching someone you love get slowly more disabled is so difficult. You're constantly in a new grieving situation. It's not surprising you get angry and resentful at times.

Simon - MS Trust: Thanks to Jo and Lisa who are now leaving the chatroom. And welcome to Lynda and Julia who will be with us for the rest of the session

Sam: Interesting reading what people have said about their relationships. Mine has changed greatly and I now see myself as a carer rather than a husband. The 'conventional' side of marriage is gone and I now look after my wife full time, including toileting and washing. I'm happy to do this for her but I feel something important is gone. I still love her, and given what she is going through, this seems a little selfish to me. But it still how I feel.

Julia - MS counsellor: Losing sexual relations can be hard for both of you. Sometimes counselling can help people to find ways to be intimate. Sometimes it means dealing with the anger and the loss first.

Sam: Yes, it is the intimacy rather than the sex necessarily.

Lynda - neurology nurse: It's a difficult transition from husband to carer and one that often happens without you noticing - sometimes it's events like this chatroom that suddenly bring it home to you. In an ideal world, you may have been able to avoid some of the personal care and had someone else to do it. But we know that life isn't that easy. Wearing two hats - husband and carer - is possible and a lady I know whose husband has MS, has an apron she wears when she's 'Carer' and when she takes it off, she's back to 'Wife'. This sounds silly, but it works for her so might be worth a try

Anne: I am coming from an entirely different point from most of what I have skimmed through. I have had MS for some seven years or more and my response has been to stretch myself physically. My husband has encouraged the various things I have been involved in (mainly walks including Edinburgh to London) but to the point that HE is the one who now ignores the fact that I do have bad times. And that makes it even harder for me to admit that I am struggling. If he doesn't want to do things he'll deny they need doing (especially housework). We no longer have dependent kids yet I find I often end up clearing up after him even though he works at home for most of the time and I also work. If I complain about being tired or stressed at work his only support is to say to pack the job in but I feel I really need the mental and emotional outlet that work provides even though it can be hard. I want to keep doing 'things' - I want to be able to look back in future years at things I achieved other than the fact we ate and had clean clothes! A marked relapse in November last year has left me feeling even more that if I don't sort myself out, no-one else will. I don't feel I can follow some of the suggestions made already - like asking someone to cook a meal - and then walk 15 miles at the weekend! Sometimes being the partner of someone who is the partner of someone with MS is hard work too!!

Julia - MS counsellor: Sometimes people divide things up, so that one says 'can' and the other says 'can't' - so you get a fight between you outside, rather than struggling with the conflicts inside (if that makes sense?)

Julia - MS counsellor: Both partners have to struggle with how much they can do, for themselves and for others. Both can be scared they can't do enough, or that the consequences of failure will be dire. A lot of what people are talking about is the losses MS brings, to both of them. It's a question of how much you can keep, what you have to give up and what you don't have to lose, but might if you're not careful. It can take a long time to sort this out. Talking to someone about how you're dealing with the MS and the relationship can help - but then, I'm a counsellor, I would say that!

Anne: No, I'm afraid that doesn't make sense to me!

Julia - MS counsellor: I meant, you and your husband might both be worrying about how much you can do without exhausting yourself, and how much you need to do to keep life good: but rather than admit it's a difficult conflict, your husband says 'give up!' and you say 'I can't give up!' You are aware you see both sides of this, but perhaps he does too, but he doesn't want to think about it. While you take one side of the argument he can take the other.

Samir: It isn't so much losses as gains from MS. I believe it to be a very character building disease which is hard to cope with

Julia - MS counsellor: Certainly MS brings gains! You might be home together with each other more - could be a gain or a loss, of course!

Lynda - neurology nurse: Change of role can sometimes bring an unexpected pleasure - the dad who used to play football with his children now finds that sitting reading with them and helping them with homework is actually enjoyable. One chap I see has actually just had an art exhibition and had never painted in his life until his mobility was affected. Obviously there are times when either the person with MS or the partner resents and is angry that this change of role has been thrust upon them, but there are also times when it can be a positive thing

Samir: When do you think is the right time to tell a future partner about MS?

Lynda - neurology nurse: To tell or not to tell - I think that if the relationship is meant to be, MS won't make a difference but if it DOES make a difference, you may be better off without it. This sounds like a cliché but I can't think of another way to put it.

Samir: Very true. If it's meant to be it will be! As the song says "que sera sera, whatever will be will be!"

Julia - MS counsellor: People are sometimes too scared of the possible consequences to talk directly to their partners. Telling someone else first can make it easier to decide what you want to say to your partner.

Samir: It is hard. It is even harder to even tell someone through fear that you may lose them

Julia - MS counsellor: You never know how the other person will see the MS; it depends on their experience of it, or what they think they know about it. It's really hard to know what to say and when to say it.

Samir: MS is a very unknown disease - most people research it on the net and hear only the worst case scenario!

Julia - MS counsellor: Some people only know bad things, but some know only good things. You really can't predict.

Samir: So what can we do to make it easier for future partners?

Julia - MS counsellor: A lot of people are afraid no-one will love them if they have MS. But people do go on loving each other, and do make new relationships too.

Samir: Is honesty the best policy? Or do you think it's better to get to know the person before disclosing MS to them?

Julia - MS counsellor: I think you were right about talking with your partner being a good thing to do, even though it can be scary. It can help to know that you are sharing the fears as well as the pleasures of life, rather than feeling that you are on your own with them. There isn't a straight answer to how or when to tell; everyone with MS I've met has had a different answer to it.

Samir: Yes, but how do you disclose it to a new partner? It is a scary prospect! Loads of what ifs! It's so subjective, just like MS is!

Julia - MS counsellor: Part of the problem is that if you say 'I've got MS', you don't know what it means to them. It might mean - like my neighbour, she was in a really bad way - or it might mean - like my boss, she was fine, she worked until she retired to the country with four children and six dogs.

Bill: Honesty, Samir. I don't think MS is something you can keep from someone you want to spend a long time with. MS is part of you (though not all of you) and, whilst it may not be a great selling point, it can't be avoided. However long you wear a hat, she's eventually going to find out that you're bald. If she can't cope with MS, better to lose her now than a while down the road when the break up will be much worse

Julia - MS counsellor: I would suggest talking to someone (a counsellor?!) about what it means to you first. This might help. If you're scared, you'll tell them in a different way from if you're OK about it.

Samir: All very true, but I feel that MS has held me back SO much already. I don't want it to keep doing the same all my life?

Lynda - neurology nurse: I love your comment about the hat, Bill. It's very true though and any relationship (in theory) needs to be based on honesty (even if you wear a toupee!)

Julia - MS counsellor: It's being honest with yourself that hurts most; your feelings about being 'bald' may be worse than theirs. You may be able to find new ways to enjoy life on your new path, rather than feeling the MS has held you back.

Bill: I think that's true, Julia. If you are hiding something (from them, from yourself), you are going to find it harder. If you are happy with how you are (even if how you are is perhaps not how you wanted to be), then that will show through

Julia - MS counsellor: Yeah, Bill! Thanks!

Samir: True, and just like MS, my feelings about the disease may be worse than a future partner's. But I still worry about it, what if she rejects me as soon as I tell her?

Lynda - neurology nurse: I'm sure that you'll find someone one day who will want you for who you are and not your diagnosis

Samir: I do hope and pray that such is the case, but it will be a hard journey, the fact that I do not have a job at the moment doesn't help either! I have joined a group for disabled Muslim marriage but my family keep saying "why marry another disabled person?" It's so hard to convince them that it won't be that bad but they all insist that I should just marry an able bodied person

Julia - MS counsellor: Part of the problem is that any health condition can make people feel bad. Whenever you tell a potential partner, they may react badly. If they pull away, they may feel bad - and so will you. You can't control that, any more than you can control the MS. As Bill says, it's to do with accepting life as it is, which includes the fact that you can't really control other people or your own body/health. There isn't a way of telling which will 'make it all right'; you have to be 'all right' about it in some sense before you start.

Lynda - neurology nurse: Is it your family who believe you shouldn't tell a prospective partner that you have MS, Samir?

Julia - MS counsellor: Joining a group sounds a great idea. When did parents ever agree to their children's ideas about who to marry?

Samir: My dad says get to know the girl before disclosing it

Lynda - neurology nurse: It needn't be the first thing you tell her - she needs to get to know you first, but if you think there is a future in a relationship, you need to be honest about it. Maybe you shouldn't be looking so 'long-term' initially when you meet someone - you might scare them off. I think your dad is right because you'll know if a girl will be able to handle your diagnosis if you get to know her first. Try not to make it so important - YOU'RE important, not the MS

Samir: Very true, but I also do not want to lead a girl on either?

Julia - MS counsellor: It is really difficult - not wanting to lead a girl on and not wanting to frighten her off. It is a moral dilemma and I don't think there is a simple answer. Life doesn't have simple answers and illness sets puzzles we can't solve without feeling bad.

Samir: It seems like another struggle with which I am going to have to battle! So many other people that I know with MS are already married and as the vows say "in sickness and in health" so what more can people do? For me it is different, I am yet to marry so I will have to find a girl to take me on?

Julia - MS counsellor: Yes! Once you recognise that life is made up of conflicts, you'll stop looking for the perfect solution - and the perfect girlfriend, of course! I do know lots of people who have MS who have found partners after their diagnosis: I hope you do too!

Samir: OK I really must go now, nice chatting to you guys

Brian: My problem is not so much with myself - my wife and I seem to cope reasonably well. It is the wider family where problems lie. Her sister never visits as he can't stand to see the effects of MS. My mother in law treats her as if she were deaf, blind and made of china - well meaning but overpowering.

Julia - MS counsellor: Brian - families can be a problem! People can marry to get away from them. It's surprising how hard it can be to understand what makes in-laws tick. People often expect in-laws to be like their own family, and are surprised when they aren't.

Brian: Their in-law status is coincidental - both my wife and myself find their reactions difficult

Julia - MS counsellor: These reactions are difficult whoever has them of course. Illness does distress some people so badly they can't bear to look at it; it can also be used as an excuse to avoid another problem in the relationship; friends and relatives can also be afraid they are going to be asked for help they don't want to give. And your mother-in-law's reaction is also difficult to handle. Can you talk to her about it?

Lynda - neurology nurse: Family members often don't have the understanding that others do. Have you ever asked your sister in law why she doesn't come or let her know how it makes you and your wife feel? Her mother is probably treating her like this because she doesn't really understand about MS. What about some good up-to-date reading material to educate them all or has this been tried before?

Brian: My mother in law is coping in her way - having a child with an illness is obviously challenging and I'm sure she vents her frustration by doing too much. My sister in law will not address MS at all

Julia - MS counsellor: I must say my experience suggests you might find it very difficult to change your mother-in-law; sorry about this! Can you find a way of laughing together about it when she's gone? (I'm finding this chatroom thing difficult - not seeing people and talking face to face! Laughing may be the last thing you can do.) It sounds like you are trying to understand her, and not doing too bad a job of it, Brian.

Brian: We try to cope - but it does mean that MS becomes very central to the family (whether by overindulgence or denial of its existence), which is not how my wife and I live our lives.

Julia - MS counsellor: There comes a point when some people find it easier to give up on relatives or friends. Trying to understand what is going on for them is obviously a good thing to do if you want to keep in touch, and you might or might not be able to change them or their behaviour. But there can come a point when living your life and just letting them be is the only thing you can do. Do you mind not seeing your sister in law? That makes a difference.

Brian: My wife and her sister are not close, but she is family and it is a discomfort in life to have that feeling of isolation from a family member

Lynda - neurology nurse: I agree with Julia - I'm sure you both have friends who don't treat her differently and you enjoy being in their company. It's her

sister's loss although obviously it's hard for you to see someone you love treated in this way. As for her mum - is it possible to make a joke of it and let her know in a light-hearted way how she is treating her? You haven't said how old your mother-in-law is so this may not be possible - I speak with experience!!!

Julia - MS counsellor: Brian, you do sound sensible. It is interesting, what you say. The denial and the overindulgence may be affecting each other. Your sister-in-law scared she'd have to do as much as her mother does if she once admitted there was anything there at all, and her mother trying to compensate for what the sister doesn't do. ?

Brian: Her mother is in her sixties and a difficult woman to divert. We appreciate what she does (really) but sometimes wish she would do less of it, or at least realise her daughter is no longer 12 :-)

Lynda - neurology nurse: It's unlikely that your wife's mother is going to change now. Is her dad still around and if so, is he able to channel her energies any differently? Or is there an MS group she could go and spend some time at nearby to maybe either learn more or be able to help in a practical way?

Brian: My wife lost her father several years ago. Her mother has read everything - and usually sent us a copy!

Julia - MS counsellor: A lot of people feel isolated from their sisters; I am sorry it is uncomfortable for you. Are you sure it is the MS which is causing it? There are lots of other reasons why sisters keep away from each other. But it's also a question of how much work you want to put into trying to change the situation. And, Brian, it is a well known fact, that I am sure you know, that parents ALWAYS treat their children as if they are about 12!

Lynda - neurology nurse: Sorry, Brian, I think you're stuck with Mum-in-Law as she is by the sound of it. Does she do any jobs that need doing and that take some pressure off you (I'm trying to see any positive input she has). If not, would she be open to doing that.

Brian: She would do everything given half a chance - that is what makes it so overpowering. We do appreciate her concern and can understand why she is like this, but it does make it difficult to spend too much time in her company.

Julia - MS counsellor: Just thinking about how MS can make people feel isolated anyway, in lots of complicated ways. And misunderstood. And it's so hard to get through that. It takes so much listening as well as talking. I wonder if your sadness about your sister in law is also connected with sadness about the isolation MS brings anyway.

Julia - MS counsellor: Has your mother-in-law found a way to limit her involvement? (By driving you mad?)!

Lynda - neurology nurse: Brian, Can you limit her visits or does she live too close by?

Brian: There is nothing limited about my mother in law :-).

My wife has lost a few people because of MS, but that we can cope with. It has shown us the truer and stronger friendships. A sibling is a different matter. I think we are OK with the MS - we cope. I suspect there is nothing we can do and must wait for my sister in law to come back to us (or not) in her own time.

Julia - MS counsellor: Does she actually feel overwhelmed herself? Would it help to be clear that she isn't expected to sacrifice herself totally for her daughter? Mothers can feel bad because they don't actually want to give up their lives for their daughters, but then overcompensate by pretending that they do.

Brian: I suspect you're right, Julia. A parent wants nothing more than to make things right for their child, and so something like MS that won't go away must be terrible for her. She is reluctant to talk about the condition in general, batting away comments by saying she's read the books. I imagine she takes it personally at some level and is over compensating like crazy.

Lynda - neurology nurse: What's her relationship like with the other daughter (who doesn't visit)?

Brian: She seems to get along well, but her outlook is to make everything right - so if there is friction I doubt she'd tell us about it

Julia - MS counsellor: It must be exhausting for your mother-in-law, trying to make everything right all the time. Do you think she feels a permanent failure?

Julia - MS counsellor: I have had mothers weeping because they couldn't 'take the MS off ' their daughters, and others weeping because they didn't want to and they felt it meant they were terrible mothers. I wonder which kind your mother-in-law is?!

Brian: I am guessing about her motives - outwardly she tries to jolly everybody up and is a natural 'do-er' - but I imagine the MS is hard for her to deal with

Lynda - neurology nurse: This is probably a silly idea but would setting her the 'task' of getting her other daughter to come round and see her sister do any good at all? I won't be offended if you say it's really ridiculous - honest!

Brian: We have mentioned family matters to her, but she tends to bat this away as she does with other problems. I think we are resigned to how things are

Lynda - neurology nurse: Brian - how about some new 'House Rules' for all visitors to adhere to? Just a thought... And try and stop her being Superwoman!

Julia - MS counsellor: Batting away problems may be the only way she knows how to deal with them. But it makes me suspect she is afraid of something. It seems that people often think they are avoiding 'reality' by denial, when in fact the problems which they are avoiding turn out not to be so bad at all, when they turn round and look at them. If you could find out what it is she thinks she shouldn't talk about, you may find her feelings and fears about it are actually unrealistically bad. But a son-in-law may be less able to do this than a counsellor.

Jenni: In Dumfries and Galloway we have the Princess Royal Trust for Carers Centres. These are centres specifically for anyone who is a friend, relative or child of someone who is ill or disabled. (It is not MS specific.) It is a place where you can go for information, advice and support. It may be worth seeing if such a facility exists near you, even if it isn't MS specific.

Lynda - neurology nurse: That sound really good. I think most areas have carers groups and young carers groups but not an actual Centre. The main

problem with attending a group, of course, is having to get 'cover' for the time you're away. I used to run a Carers group but it sometimes got a little 'competitive' with some people feeling they provided more care for their family member, and others left feeling they obviously didn't provide enough!

Simon - MS Trust: Both [Princess Royal Trust for Carers](#) and [Crossroads](#) provide services for carers. If you follow the links it will take you maps of their centres around the UK.

Donna: Hi everyone, my mum was diagnosed with MS last year she has been dealing with it really well she is now doing a parachute jump on 6 June to raise money for the Ms Trust you can view her online page at www.justgiving.com/valeriewestbeattie

Simon - MS Trust: Thank you and good luck to Donna's mum

Lynda - neurology nurse: Your mum sounds amazing! I've always shied away from the parachute jumping fundraiser so you must be really proud.

Donna: Thanks. She just feels the support and information she has had from the trust has been invaluable and wants to give something back. I am really proud. I'm nervous too. We will be going along to support her. I think I'm going to be more scared watching her but it's been really positive for her she is really looking forward to it.

Julia - MS counsellor: Well done, Donna! It's great that you can be there! Mothers do like it when their daughters appreciate them!

Lynda - neurology nurse: You'll have to arrange an 'After the Jump' party to celebrate, and get everyone to bring something to eat (to save work on your part) and have a sponsor form handy in case you've missed anyone. Has it been in the local paper? A young chap I see with MS made loads more once it had been in the paper.

Dave: I do quite a bit of work with CAMRA and last year we raised £400 for the Trust, and hopefully this year will do it again. The people who brought the display were really grateful and left us with some very good literature.

Kate: A couple of years ago the PCT funded a place for me on the pilot of a course about grieving unrecognised losses. This has now been developed and expanded into a course called Emotional Logic. It is also useful for developing creative conversations that overtime can deepen relationships as hidden losses or unacknowledged losses are named. This helps find constructive ways of dealing with situations for both parties. EL can be done by distance learning.

Julia - MS counsellor: That sounds interesting

Margaret: I know this point isn't very pertinent but I really would like to know. I was diagnosed eight months ago. I live in Spain, my hubby is Spanish. He is also 75 so I doubt he will be caring for me for very much longer. My sister in Scotland has said she will care for me when/if I can't manage alone. So I will obviously end

up in Scotland. Here I have been prescribed with Rebif. Will I be eligible for the same treatment in Scotland? I have lived abroad for 35 years.

Lynda - neurology nurse: I'm fairly certain you will be eligible although not 100% as Scotland varies significantly in some aspects of Healthcare.

Julia - MS counsellor: Some sisters are great, Margaret! (Actually, I'm making a big assumption here!) Sorry, I can't help you about the Rebif!

Margaret: My sister is the best sister anyone could hope to have, and she has married the best brother in law going. I am doing my damndest to keep mobile and fit and not lean too much on my husband, but it's very difficult.

This is a great idea. So nice to be able to talk and ask questions. I wish you would do it more often.

Simon - MS Trust: We usually do a couple of chatrooms a year on a chosen topic. The next one will be in the autumn. Send your email address to info@mstrust.org.uk and we can add your name to the list to receive reminders about upcoming chatrooms.

Kate: Earlier there were exchanges about paying for physio. I pay for a monthly visit from a yoga therapist. It has been really useful in helping keep me flexible, and helps keep hips properly aligned as one side gets affected by spasm.

Jane: I have been looking on and off all day and think there have been some really interesting topics on here as well as a lot of obviously strong people (both with MS and partners) going through a whole range of experiences.

My other half was only diagnosed in January though something happened last year that meant MS was suspected so we were kind of ready for it. We are incredibly lucky he has relapsing/remitting MS, which has been picked up relatively early and he has recovered well from the attacks and is on disease modifying drugs now.

Just to pick up a bit on things other people have said, he decided to opt for private neuro-physio early on (even before diagnosis) and although expensive it seems to have been extremely worth it in his case - we happily exchanged our holiday for it as it seemed to work for him. We are both still working and able to manage our household OK but it is good to know that there is help out there and we would both have a right to have our needs assessed should things change.

Julia - MS counsellor: Mm. I'm talking to Jane and to Brian from earlier here. There is something so reassuring about being able to do something. And it's good while the person with MS gets better or does well. The problems begin when people start thinking that their efforts to do the right thing have failed - and this must mean, for example, that they have failed, they are bad, or whatever. Jane may never get to this point, of course, and I hope she doesn't. But Brian's mother in law seems to keep trying, desperately, rather than face the terrible distress of recognising that what she does cannot stop the MS entirely. She may feel terribly isolated herself, not able to let anyone know how bad she feels, including herself.

Lynda - neurology nurse: Good to hear your positive views but sorry you've got to pay for physiotherapy. There are so few good neuro-physiotherapists in the

NHS and most are only allowed to offer so many sessions - usually six. Glad the injections are doing their stuff

Kate: Julia's comment seems like a situation that Emotional Logic could help, as it does include accepting with sadness situations that can't be changed. Until that happens it is hard to use one's energies in new ways

Julia - MS counsellor: Jane, just re-reading your posting, I'm wondering about you giving up your holiday for your husband's physiotherapy. That kind of self-sacrifice is great in the short term, and wonderful of you, but you may need to find another way to deal with MS in the long term. Partners need to be looked after, just as much as they did before. You need to allow your husband to look after you, and you both may need your holidays too. Being too self-sacrificing, as Brian's mother-in-law is (above), gets uncomfortable for everyone eventually - new partners, take note!

Jacey: I do not go out because my ex-husband lives around the area and he also does DIY for people near to where I live. We were together for 19 years and he was gradually more miserable. Whereas he always said 'we' had MS, he didn't do any research into it and never had time to just listen. So yes, he got his unspoken way eventually and I left. I am so glad that I haven't got that guilt about making him suffer now. But, my goodness, I do miss male company. And I don't mean just sex, I mean being cared about - though it has never been the case with a partner. I have given up trying to find a good kind man. If they are about, they are not who I want. Do not know what I'm saying. Just life is a bitch and then you die!! But when! Only joking. Got a good family. Just so tired!

Julia - MS counsellor: Hi Jacey, glad you've got a good family! Do you want to do something about not going out? Are you happy that way, or are you beginning to resent the fact that he 'got' the street as well as whatever else, when the marriage broke up? How long ago was it?

Lynda - neurology nurse: Sorry you've had such a rough deal and you feel not able to go out because of your ex - what is it that you're worried about if you see him? How are you dealing with the tiredness and have you got an MS nurse you can offload onto? Sometimes medication can make all the difference and she might be able to help

Jacey: I don't go out because getting my scooter out of the flat I now live in doesn't have a ramp. An occupational therapist came months ago and I haven't heard any more since. I phoned and was told she couldn't find one. I have a promise of one from a nephew. Maybe I'll get it in five or so years. I don't mind staying mainly in my lovely flat - I am safe and have all I need close by.

Julia - MS counsellor: I'm horrified that you haven't got a ramp! Get back to your occupational therapist immediately! Seriously, you really shouldn't have to pay for one.

Lynda - neurology nurse: Jacey, you MUST get a ramp sorted. Think of the fire risk if nothing else. Actually if you demand a risk assessment, it will be done in a shot!

Jacey: I may add that the reason I dread bumping into my ex is that he found a dolly bird two weeks after we split. If they were walking through town and saw me on my little scooter, I would feel so awful! My ex also learnt that my daughter

has been diagnosed with MS as well. He never got on with her and I can hear him saying to his dolly bird "See, what goes around comes around!" I hate feeling like this. I do not have an MS nurse. Mine left in February and I haven't heard of another one. I see my neurologist every six months. My new GP has little knowledge of MS. I have a good friend who is always there for me. She is calling in here today. I will be fine tomorrow. But thanks for listening.

Julia - MS counsellor: Ow! I do sympathise, seeing your ex with a new partner would of course hurt like mad.

I'm glad your flat is lovely. It's interesting - I'm not sure if it you are OK shutting yourself away, or if you need to think about getting out. People sometimes don't realise how much they are restricting themselves, and how much it is costing them. But perhaps you do know, and you are OK about it. Generally, people feel better and see the world differently when they meet other people. Talking to people is a good antidepressant, but perhaps you aren't depressed, and you just enjoy talking through the internet? But I think you do sound a bit down. Can you find some way to get out? You need to meet other people on scooters, who are not ashamed of themselves for existing. It does sound as if you think you brought the MS on yourself - did anyone tell you you didn't? You need a counsellor as well as a ramp!

Lynda - neurology nurse: I'm sorry to hear that you're daughter has been diagnosed as well but I'm sure you're going to be a great role model for her. You need to be getting out and seeing the world again and if you see him and the new dolly bird (and they don't stay new forever!), you can be thankful that he's someone else's problem now! Please get that ramp sorted and I've enjoyed talking to you and contact the MS Trust tomorrow and see if your nurse was replaced

Simon - MS Trust: Jacey, if you want a positive image of people with MS who use scooters, I can recommend you read about the [Red Wheelies](#). They are a scooter display team who are gearing up to travel the length of Hadrian's Wall as a fundraiser for their MS Therapy Centre and to raise awareness of MS.

Margaret: Is there medicine for fatigue?

Lynda - neurology nurse: Margaret - there's amantadine and modafinil for fatigue. Amantadine is usually much easier to get on prescription than modafinil but some GPs are happy to prescribe. The MS Trust has a great publication on fatigue management called 'Living With Fatigue'

Margaret: I was wondering whether the medicine I have for high cholesterol is making me more fatigued as it does mention this in the prospectus. Do tranquilisers have the same effect? Also is your memory affected by either of these drugs? I ask because I have gone right downhill in the last six months. Or could this mean I am changing from relapsing/remitting to progressive?

Lynda - neurology nurse: Maybe you need to get your statin changed. They can make you fatigued and definitely tranquilisers have this effect. Have a word with the doctor and get it checked out

Julia - MS counsellor: Fatigue affects people with relapsing/remitting as well as progressive. In my experience it doesn't behave quite like other symptoms, coming and going over a period of six weeks or so. It is a bit strange and

unpredictable. Partners and family members don't understand it either, and they often forget to take it into account - particularly if they can't predict when it will happen either. It gets boring, telling each other all the time, whether you are tired or not.

Margaret: I think I will suggest to my doctor that I stop both of these medicines. My cholesterol isn't too bad and I don't know why they prescribed tranquilisers. I have come to terms with my illness.

My fatigue is not mental fatigue. It's my legs that will only walk or stand for 15 minutes max. Then they give up and I am in danger of falling. My balance also gets considerably worse. Is this a different type of fatigue?

Lynda - neurology nurse: Margaret, do you have access to physiotherapist or maybe you can get the exercise book from the MS Trust (it sounds like I'm on commission doesn't it?!). Exercise can really help with fatigue

Simon - MS Trust: Lynda's doing a grand job. We have two things for exercise - the book Exercises for people with MS and a DVD starring Mr Motivator called Move it for MS

Dave: Fatigue being a treatable symptom - that is really good to know. My wife has primary progressive, diagnosed approximately two years ago, and can fall asleep on the sofa through fatigue. She still works in a school and comes home and starts again, even though we try to help. She feels she has to carry on regardless.

Margaret: I go to a rehab class in the pool every morning and privately to a physiotherapist once a week. She is excellent and teaches me exercises to do during the week. One point to show how beneficial she is to me - I was considering getting a new car that was adapted because I couldn't move my foot from the accelerator to the brake easily. She started me on certain exercises and now I have no problem at all. I can also walk on tiptoe which I have been unable to do for 20 years. I am quite sure the exercise I do contributes to the fatigue but at least it keeps me without pain, flexible and in a good mood.

Lynda - neurology nurse: Dave, it's worth getting some advice about fatigue and some medication if appropriate. Some occupational therapists will give advice on fatigue management

Dave: My wife only takes showers as she cannot stand the heat of bathwater on her legs, where I would think sometimes a soak would be beneficial.

Lynda - neurology nurse: A soak in a hot bath is usually not a great idea and most MS nurses would suggest that showers are much better. Soaking in hot water really CAN increase fatigue levels considerably, so I hate to say this Dave, but - she's right!

Julia - MS counsellor: Just read your posting re your wife's fatigue - there is a risk that people find themselves giving up social life in order to hang onto their work, because it hasn't occurred to them that they might actually prefer to cut down their hours in order to protect social time, or time with the children or with their partners. Just a thought. Work may not be the first priority - though it might be, of course, depending on your situation.

Dave: There was a time before my wife was diagnosed, that I used to walk in front of her. But now, I follow behind waiting for a stumble to catch her! We jokingly say she is break dancing again!

Kate: I experience two types of tiredness - one I think of as the nerves habituating due to demyelination and if I rest for ten minutes they seem to recover (though that does not work as well by the end of the day) and the other an exhausted tiredness, which I put down to all the extra effort needed to do things. I'm learning that often the exhausted tiredness often needs a half day really resting and then the next day I feel loads better.

Dave: My wife agrees with your comments, Kate. Sometimes not even half a day resting is enough for the exhausted tiredness. She also has spells of dropping things and being unable to hold a knife to peel vegetables or to cut up food.

Lynda - neurology nurse: It's amazing how quick your reactions become if you think someone may stumble. How does she manage when she's on her own, ie at work?

Dave: Her words - "she just gets on with it" and it takes extra concentration to stop herself from falling, which causes more fatigue. A vicious circle!

It's really hard dining out now! My wife has to be selective in what she orders because she may struggle cutting up food! She has trouble peeling vegetables and preparing food at home, so I find myself doing more and more which I never complain about.

Lisa: This is a really interesting conversation. My partner was diagnosed two years ago at 32. We obviously couldn't believe it at first. He was working full time but now gets so exhausted he has had to quit his job. I'm sure there are plenty of others in the same position. He is finding it hard to know what to do with his time. Any suggestions of how others have coped with this would be really helpful

Julia - MS counsellor: How are you coping with it, Lisa?

Lisa: I'm doing OK. Sometimes I get frustrated and like other people have said feel guilty. I just want him to be happy. He finished his masters last year, which at times was a struggle for him but he graduated, and now he kind of seems lost with no direction. He has a part time job, but needs something more to occupy him.

Margaret: Lisa, get your partner to start playing bridge online. It is a fascinating game and a great bunch of people from all over the world!

Lynda - neurology nurse: Hi Lisa, fatigue really is the great unseen symptom that is very rarely understood by other people. There are loads of reasons for fatigue, but get in touch with your MS nurse if you have one, or download the information from the MS Trust. It IS a treatable symptom a majority of the time but you need advice. It's one of the reasons for people having to leave work and has a huge impact on other symptoms eg cognition, but do get some advice and help

Lisa: He just started on the fatigue medicine last week after seeing the MS nurse. I'm told that it can take a few months to see a difference. Hopefully that will be beneficial. I think too he played so many sports and now finds it very difficult.

Even after an hour walk with the dogs he ends up sleeping for three or four hours. I think it's hard for other people to realise how tired people with MS actually get. I know I don't really comprehend but I'm trying to read as much as I can to really get an insight into the disease.

Also we have been invited to attend all kinds of MS Society events in our area, but he won't go. He says he knows he is ill but doesn't want to sit with a bunch of other people who are sick to remind him of it. I think it might help him and me but he isn't interested.

Julia - MS counsellor: I think you are trying to make it better for your partner. That is a hard thing to do. Don't be too hard on yourself if you don't succeed. He (and you) have to go through a period in which you feel awful and miserable before you come out the other side - but most people do come out the other side eventually. People do get better at living with whatever they have over time. Partners often try to take over responsibility, but that can backfire because the people with MS can have problems with that

Lynda - neurology nurse: It often takes time to be comfortable around other people with MS although he may never want to attend a group - some people don't. On the subject of fatigue - does he sleep at night as this makes a big difference to fatigue levels? Does he wake early? He might be depressed although probably won't want to admit it

Lisa: Yes, I do try to make it better. We were/are so sporty and I can still do everything and he can't. I think the worst thing is I get frustrated at times because he is slower or gets tired quickly. Even though I know why, I still get frustrated. I suppose I feel guilty that it is him and not me that has to deal with it but also feel selfish because no one realises how hard it is for me sometimes to have to do the things he can't. For a while he lost his vision and that meant all of sudden I was responsible for everything and I found that hard. Thankfully he regained it after a few months.

Julia - MS counsellor: I do recognise the struggle Lisa and her partner are having. It is so hard not to try and take over, especially if he's tired all the time. It is sometimes a problem people bring to me - the husband hates being pushed to do things all the time, and he just starts feeling persecuted by his wife as well as the MS, and he digs his heels in. I know it's hard, but letting him take his own time (and it might be two years) to come to terms with it, may be all the wife can do. On the other hand, Lisa, you might be able go to MS Society meetings for you; for you to understand how he is behaving and feeling. And to meet other partners, perhaps? You have needs too.

Simon - MS Trust: If going to actual groups is a problem, maybe some of the online groups may be easier to handle. There are quite a few, such as [Jooly's Joint](#), [MS People](#) or the [MS People UK discussion list](#).

Maybe there are other sports or activities that you can try that don't trigger the fatigue as much. Have a look at the suggestions in the [Staying Active](#) pages of our website.

Lisa: Thanks for that Simon I will give those a try.

Julia - MS counsellor: That struggle - 'I can still do it and he can't' - is awful. You have to cope with your own feelings about whether you would be jealous or envious if it were the other way round. Would you hate him if he could and you couldn't? Does he hate you for it? Or not? Not everyone does, but some do. And

it can change over time. You have to decide whether it is OK to go on doing it or whether he gets too bad tempered, or whether you would get too resentful if you stopped, and a hundred other feelings.

The interesting thing is to actually ask. I find partners often don't know how their other half thinks and feels; they just assume they would feel like they do. And this isn't always true. One family I know stopped going to the seaside because the wife thought it would hurt the husband too much to see the children playing in the sand when he couldn't join them. When he found out he was angry; he said he loved watching them, even though he couldn't join in; it was better than not doing it. I think time, and personality, play a part in these things.

Lisa: I run marathons and half marathons and he is really supportive. He can run about three miles with me so helps out with training in that way. He never ever gets bad tempered, which is great and we have discussed it and he says he is glad I can do the sport I love. For him, he gets more frustrated than anything that he can't do it. Generally he is really positive and just enjoys what he can do. Recently he has been losing his balance a lot and dropping things or breaking things. He dropped a tin of white paint all over the carpet last week. He called me at work to tell me. I said it's only a carpet. When I got home he was in tears. I thought it was because he had lost his balance, fallen and knocked it over but he said it was just because the carpet was ruined. It doesn't happen very often but every now and then things get too much for him and he breaks down. Then from my point of view it's just a feeling of helplessness and whatever ever I say I can't make it better.

Julia - MS counsellor: Lisa, you have described it so well! The feeling of being so useless when he cries; everyone has that. MS may be the first time someone realises there is something which can't be mended. And a carpet is so symbolic; it makes you feel warm and comfortable and ordinary - like not having MS.

Lynda - neurology nurse: There probably wasn't anything you could have said that would have made it better. It's true - it IS only a carpet, but that could have been the last straw in a day when loads of other things went wrong. Put in an insurance claim and have the whole room re-carpeted in a colour to match the new paint. It's really difficult, I know, when there are times where whatever you say isn't going to make it right, but there's nothing you can do to change that. It's the same in all relationships - even ones without MS - so don't beat yourself up

Julia - MS counsellor: Fatigue really is one of those things it helps to discuss; to work out what brings it on and what makes it better. It is so clear from this chatroom that MS is a partnership thing; it's something people have to learn to cope with together. And that means learning to cope with the distressing feelings too. Do you go all sensible, and think about what you can do, or do you weep about what you've lost? In my experience, one needs a certain amount of both. First you pretend it isn't there; then you weep; then you get on with it? (But I don't really believe in generalising, because everyone is different!)

Lisa: Yeah at the end of the day, you have to get on and make the best of it. We are planning a trip to Japan next year as he has always wanted to go. We are both looking forward to it.

Julia - MS counsellor: About crying - I was also trying to say that (particularly in the first two years after a new diagnosis or significant symptom) people sometimes find themselves caught out by their own distress. They may cry over a weepie film that previously wouldn't have affected them at all. I think that

normally people keep a lot of miserable feelings at bay, but that when they are given a chance they latch onto a more minor reason for being upset and can come out in weeping which seems over the top. And it is. You're crying for 'everything', not just the pot of paint or the carpet.

It can help to name and describe the feelings of loss and misery; because while they are unnamed they often seem much bigger and they can come out in the middle of the night and frighten you more.

I think the song 'Yesterday' is a really good description of facing a loss, like Lisa's partner is. It takes some time before you can move on; you need a place to hide away for a while first. And to be able to believe in yesterday.

Jane: Thanks to everyone who had helpful things to say. I totally agree that in order to be good partner and any kind of support to someone with MS you need to look after yourself too, so know that giving up of holiday is just a short term solution. I grew up watching my mother care for a disabled sister and dying partner so know how important it is to have respite and recharge your own batteries. Luckily our lives aren't that different to 'before' yet!

In terms of the honesty discussion, we have decided to go down the totally open route. Most family and friends have been great and taken the time to read accurate information when we've directed them to it. Also the job that my other half does means he is in quite a notable position in the local community - he has effectively announced his diagnosis so that (as was mentioned earlier) people don't think he is drunk, forgetful or rude when he is having a bad day with the symptoms. Help has been offered from many sides and he has accepted some whilst keeping appropriate boundaries in others, which is quite an art. The only downside I can think of for accepting a label/letting everyone know is that people do constantly cut out those press articles for you or tell you how the aunty Janice 'cured' her MS by changing her diet or something.

Jim: Yes, there are so many cures in the press it's a wonder anyone still has MS! All the well meaning friends and relatives with the remedies seemed annoying at first.

Julia - MS counsellor: It was one of the first things people told me about having MS - that everyone has a 'cure' to offer!

Dave: If you're anything like me, you see all these cures and think "why isn't it happening for us".

Jim: Dave, we started like that, but got used to the fact that some were stories blown up out of all proportion by the press and that most were things that work for the individual and that nothing works for everyone. Of course, some are sharks feeding on the hope of people with an incurable disease.

Lynda - neurology nurse: I sympathise with you about the articles and you'll find that Tuesday's Mail will ALWAYS have something in it on MS! You DO need to look after yourself as a fatigued and resentful partner is not a good person to live with. When people ask how your husband is, you need to get in the habit of saying either "We're BOTH well thank you" or "He's fine but I'm absolutely exhausted so if you're offering to help in some way - that's fantastic news!" Over to you...

Dave: Lynda, that was brilliant! I must remember that one.

Kate: I find it useful to have some shorthand phrases to convey when certain things are happening to me, like "you need to be psychic now" when my speech slows and I start saying the wrong words! It does save problems, and the right words comes back when I'm not so tired

Jim: Within the family we use the word 'hedgehog' for forgotten words. My wife remembers that when the actual word she is looking for is missing. It prevents her from grinding to a halt as she searches for the word and often we know what she means from the context. The whole family does this now.

Simon - MS Trust: We're coming to the end of today's session now

Lisa: Just a big thanks to you all and everyone who has contributed. It's great to be able to talk freely to people who understand and are going through similar experiences.

Dave: I have been reading most of the script today and have felt myself welling up! Sometimes you feel so useless. Unable to grasp what has happened. I am an 18 stone 6ft toughie, and can be reduced to tears by most of what has been said today! I wouldn't have missed this for anything!

Jacey: I feel ashamed that I've moaned and just wanted to say thank you to all of you. It is great to chat online and the MS nurses sound lovely. My friend has been and cheered me up as always. I am now off to dream of the days I could dance and run and walk even! Still I shall be more positive when I wake. Thanks for being there.

Julia - MS counsellor: I've really enjoyed reading everything people have said. Thanks for inviting me to join!

Lynda - neurology nurse: Thanks to the MS Trust for hosting this. It's been really good

Simon - MS Trust: Thanks to everyone who has contributed to the room - Julia and Lynda, and Jo and Lisa earlier in the day. And to all the partners and people with MS who have shared their thoughts and experiences.

The transcript will be available in a couple of weeks from the Chatrooms page

Resources mentioned in the chatroom

Other than our own publications, the MS Trust can not vouch for the content of the information listed

MS Trust

Books

- Exercises for people with MS
- Living with fatigue
- Move it for MS (exercise DVD - £1)

Factsheets

- Cognition
- Fatigue
- Low Dose Naltrexone (LDN)
- Pain
- Talking about MS

Chatroom transcripts

- Cognition

Website resources

- I am a partner of someone with MS - www.mstrust.org.uk/iam/apartner.jsp
- Map of MS services - www.mstrust.org.uk/information/services/
- Staying Active pages - www.mstrust.org.uk/information/stayactive/

Open Door articles

- Blokes taking - May 2009, pp10-11
- A partner with MS - November 2001, pp6-7
- Defining boundaries - November 2001, p7

Open Door is the MS Trust's free, quarterly newsletter

Jo and Lisa have also written for the Way Ahead newsletter for health and social care professionals

- Men are from Mars: building a group for male relatives of people with MS - January 2009, pp10-11

All of these publications are free (unless stated)

To order MS Trust publications or to join the Open Door mailing list:

MS Trust, Spirella Building, Bridge Road, Letchworth Garden City, SG6 4ET
01462 476700
info@mstrust.org.uk

Contact the MS Trust Information Service
01462 476700
infoteam@mstrust.org.uk

Other resources

Online MS groups

- Jooly's Joint - www.mswebpals.org
- MS People - www.ms-people.com
- MS People UK discussion list - <http://tinyurl.com/mspeopleuk>
- MS Trust Facebook and Twitter groups - <http://tinyurl.com/rygls3>
- MS Society's Discussion Boards - www.mssociety.org.uk/a_chance_to_talk/
- Shift.ms - www.shift.ms

Other information

- Carers' organisations
 - Crossroads for carers
0845 450 0350 / www.crossroads.org.uk
 - Princess Royal Trust for Carers
0844 800 4361 / info@carers.org / www.carers.org
- Emotional Logic - www.emotionallogiccentre.org.uk
- Independent Living Funds
0845 601 8815 / funds@ilf.org.uk / www.ilf.org.uk
- MS Society branches
0208 438 0700 / www.mssociety.org.uk/branches/index.html
- Red Wheelies
01227 470876 / redwheelies@googlemail.com / www.redwheelies.co.uk