



Fatigue

Chatroom

28 April 2010

www.mstrust.org.uk

Fatigue

28 April 2010 - 10am to 7pm

- **Nikki Embrey** - *MS nurse*
- **Michelle Ennis** - *occupational therapist*
- **Jane Goldberg** - *MS specialist practitioner*
- **Denise Middleton** - *MS clinical specialist*

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

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

Index

I wanted to hear other people's thoughts with regards to fatigue and see if I could pick up any tips	4
Managing tiredness and work	5
Adapt to fatigue and compromise	6
I sleep at least 12 hours a night but never wake naturally or feel refreshed	6
Energy saving techniques, prioritising and delegation	7
What do you suggest for aerobic exercise?	8
My general weakness and tiredness make me concerned about giving birth	9
I find the unpredictability of fatigue really bothersome	11
Short term memory and concentration problems	11
Medications / mood swings and fatigue	12
Fatigue in my jaw whilst eating	12
Disturbed sleep patterns	13
Work and fatigue	13
In the last couple of years I have definitely got more tired	14
Chinese medicine	14
Once I go to sleep I can 'switch off' for up to 12 hours and feel listless all day	15
Vitamin B12	16
Fatigue, heat and work	16
Acetyl I-carnitine and alpha lipoic acid	18
High energy drinks	19
Chronic fatigue syndrome (CFS)	19
What do people feel about amantadine?	20
Do brain trainer games have any effect?	20
Why does my head keeps nodding?	21
Drugs that help fatigue without keeping you awake at night	22
Taking breaks	22
Does fatigue keep appearing after less and less activity?	22
Pacing yourself	23
Thoughts on homeopathic remedies for fatigue	23
How can I help my partner with MS?	23
My meter has run out and I need 50p to recharge it	24
How can I help my partner with MS	25
Is there any medication that can help fatigue?	27
Exercise, activity and guilt	28
Stress and sleeping patterns	29
Every evening around 5-ish my legs seem to give up	30
I find one of the hardest things is trying to explain fatigue to colleagues	31

Finding an MS nurse to help manage fatigue	33
My medication has never been reviewed	34
Problems at work due to fatigue	34
How to explain MS fatigue	37
Interactive services for people affected by MS	37
Steps to managing my fatigue	37
Taking breaks and adapting to fatigue	38
Working, caring for a son with autism and poor sleep	40
Amitriptyline	40
Chinese supplements and power naps	41
Getting tired just standing	42
Yoga and pilates	42
Exercise can help fatigue	42
I've been invited to four weddings this year. Any tips for surviving the day?	44
I am always tired. Is there anything I can do to help myself?	44
Fatigue is like a jigsaw	44
I suffer from fatigue even though I go to bed at 9 o'clock each night	44
Advice on breathing problems	45
How can I exercise without being utterly wasted at the end of it?	45
When fatigued I get quite frightened as I feel on my last legs	46
Would FES (functional electrical stimulation) or EMS (electro-muscular stimulation) help with fatigue?	47
Fatigue and depression / antidepressants	47
Why I get tired and need to rest and then can do things again	48
Fatigue so you just want to stop and lie down	49
Taxi Card	49
Hyperbaric oxygen and fatigue	50
When I get fatigued my thinking goes fuzzy	51
Heat and fatigue	51
Fatigue / menopause	52
Resources mentioned in the chatroom	54

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

Simon - MS Trust: Welcome to today's chatroom about fatigue and MS. Fatigue is a very prevalent symptom of MS. Share your thoughts and questions with health professionals and other people with MS.

Laura: I wanted to hear other people's thoughts with regards to fatigue and see if I could pick up any tips

Simon - MS Trust: How does fatigue affect you?

Laura: I work full time and work from home on Wednesdays. I get up at 7am and I find by 9pm I'm ready for bed. Before MS I never used to be like this and I'm only 29! It's because I'm really tired. At the moment I have problems sleeping as well, so come 3am I am awake!

Nikki - MS nurse: What keeps you awake at night? Is it getting up for the loo?

Michelle - OT: This is such a common story for people with MS - the feeling of just not having enough energy to do all you need and want to do. It can be related to many things - sometimes due to MS symptoms, especially (even mild) weakness or stiffness in the arms/legs can mean things take more energy to complete so we run out of energy quicker. So taking short breaks within the day can help with this. Have you always had difficulties sleeping or is this new?

Laura: This is a new problem with sleeping at night, although I've had it for about six months now. I don't tend to wake up due to needing the loo, I just wake up naturally and then I'm awake for a couple of hours! Then I have to get up for work at 7am and am yawning all day!

Michelle - OT: Because fatigue is such a common problem in MS we tend to think any tiredness is related to the MS, but just waking up every night at 3am will contribute vastly to you feeling lacking in energy. Have you tried using relaxation techniques - you can download or buy CDs that take you through a series of simple movements, or take you on an imaginary journey. These techniques can definitely help get you back to sleep. Also by doing something like this you are avoiding doing that thing where you keep looking at the clock and calculating how long it is until you are up for work! Thing is these techniques take a lot of practice to master - but it is worth the effort. What do you think?

Debbie: Laura, I am 33 and also suffer from fatigue. There are times when I have it under control and times when it is all over the place. At the moment it is all over the place and like you in bed by 9pm and up by 4am.

I work full time over four days, two of which are at the office which is an hour away and two of which are at home. On the days I work from home I am certainly less tired.

I did try fatigue drugs they but did not seem to make a difference, however last summer I had six weeks holiday from work and got my fatigue under control and felt fab and on top of the world. This probably lasted until the New Year.

I am just getting back to normal after a relapse and back to square one!

I know with carefully planning (well hopefully) I can get back to that good place. My tips that have worked have been:

1. Split work time between office and home
2. Get funding so able to get to work by cab rather than drive/public transport
3. Book the last Thursday of each month off work as annual leave so every month will have a long weekend
4. Buy extra annual leave so can take more time off in the summer and recharge batteries
5. Accept it when I am not able to sleep and not wind myself up. Rest body by just reading and not getting brain too active at 'odd' times of the night when awake.
6. Get someone in to do cleaning/ironing so no tired out form doing tasks that can be done by someone else.
7. Have food shopping delivered to my door!

Would still love to hear what other people do and any further suggestions to combat this

Laura: Debbie, thanks for your tips, they are great. I do get my shopping delivered, which helps a lot, and I'm going to get a cleaner to help with the usual chores as this will help me as well I think.

Michelle - thanks, I haven't tried relaxation techniques, but I like the idea. I treat myself to a massage once a month and love it. So maybe the CD will help

Simon - MS Trust: The MS Trust's exercise DVD *Move It For MS* has a section on relaxation, and I should point out that Michelle is the author of our book *Living with fatigue*. And Nikki wrote our new book on self-management called *MS and me*.

Nikki - MS nurse: The self-management guide will help deal with issues like fatigue management, relapses and recognises the importance of setting yourself goals to achieve. It takes time but is well worth the effort.

Ellen: I am trying to work out how to manage tiredness and work. I am in the process of returning to work gradually, but don't know what I should do about my problem with tiredness and concentration problems. Any tips and guidance would be wonderful.

Nikki - MS nurse: Hi Ellen how many hours each day do you work?

Michelle - OT: Often the key to managing things in work is pacing. Have you got much scope in work to be able to spread tasks that require a lot of concentration throughout the day? How supportive is your employer, what type of work do you do?

Ellen: At the moment I am employed three mornings a week, having been off for about a month. This has ended up at least two days in a row to work around meetings I should attend. This week it has been Monday morning, Tuesday

afternoon and this (Wednesday) morning. I have counselling on Friday mornings at the moment and occupational health have told me I should take the whole day off. My employer is supportive

I have to say that I am working through the issues I have with asking for help, and not wanting to appear 'weak' and 'ill'. There have been big changes in my department, which hasn't helped me! And my new line manager has just left.

Carole: Morning all, I was diagnosed with relapsing remitting MS in 2008 when I was 38. I felt badly fatigued most of the day continuously for about the first six months prior to and after diagnosis. Since then though, I may have the odd day or week but it hasn't been as severe, mainly because I changed my lifestyle to help alleviate the fatigue symptoms. I found it hard going to do this and fought it, but with the help of MS nurses and the MS publications I was able to adapt and compromise. I shall be back later to see how things are going, just going out with my Labrador, Harvey, for a walk in the lovely sunshine

Nikki - MS nurse: Carole, it was worth the fight you seem to have adapted really well and taken control back.

Sandra: Morning everyone. I have a lot of problems with fatigue. I sleep at least 12 hours a night although I always have to get up to go to the toilet. I fall straight back to sleep and never wake naturally or feel refreshed. I start the day tired and end it exhausted, with some peaks and troughs in between. I would love to feel energised at least some of the time and regain my old 'get up and go'

Nikki - MS nurse: Are you on any medications that may be making you more tired? Do you manage to do any exercise or is it too much of an effort?

Ellen: Hi Sandra, I recognise what you are saying! I tend to sleep in the evening, get up and go to bed! I wake in the night sometimes, which is not new for me. I don't lie there worrying, but get on the computer and do some mind numbing browsing or FreeCell - nothing stimulating. I have watched boring night-time telly too.

Sandra: I take amitriptyline and propranolol daily for pain and tremor control. Pain relief as required. No other regular medication. I was diagnosed in 2005 and the jury is still out on whether my MS is relapsing remitting or primary progressive. Pre MS I was like the Duracell bunny 24/7 but over the past five years I find fatigue becoming worse and worse. I do try to exercise every day. I live at the top of a hill so even just walking the dog is a fairly good workout... at least coming home!

Nikki - MS nurse: Obviously the amitriptyline may be making you more tired. Taking it about one and half hours before bedtime can help you feel less drowsy the next morning. Aerobic type exercise - increasing the heart rate is good to lessen fatigue as you are doing. Diet is also important - fresh fruit has natural sugars and longer lasting energy is gained from fruit snacks

Michelle - OT: Walking is great - people think you have to be going the gym to be exercising but thus just isn't true. Trying to fit in some exercise will be helping with managing your fatigue, so even though it seems hard keep at it. As we become more unfit, activities we do take more energy - so we become more

fatigued. It's OK to sometimes do less if you are feeling more tired or have other commitments - but it will be helping.

Ellen: I am worried about doing too much, and making myself worse both physically and also in terms of tiredness. There is a balance, but I haven't worked that out yet!

Nikki - MS nurse: As everyone with MS is different it's important to listen to your body. You are right, there is a balance and you will determine this in time. It is important to work with your MS professionals too, as they will recognise the problems and help you make the right adjustments.

Geoff: I think balance is the thing. I used to want to do it all and got frustrated. Slowly I worked out that there were some things I wanted to do more than others and this helped me save my energy to achieve things

Nikki - MS nurse: Yes you are right. Energy saving techniques are vital. The book the MS Trust produces are excellent for providing tips for energy conservation. There is also a section in the *MS and me* self-management guide on living well, with useful information on activity and exercise and food and drink and health awareness

Michelle - OT: Wise words, Geoff. I think it is always important to take some time to make a priority list of things you really need and want to do and focus your energy on them. Can take a while to get this balance but it is achievable

Geoff: It's the psychological barrier that I found hardest. Not doing everything felt like admitting defeat and it took time to realise that in fact this meant I could get important stuff done rather than doing a bit of everything and running myself into the ground

Nikki - MS nurse: Delegation is the key. Getting rid of stuff you don't NEED to do, prioritising the important things, and treating yourself when things go well

Debbie: I totally agree that getting the balance is spot on. If you have been busy doing things all day it is normal to feel tired - as my husband constantly reminds me.

I am extra tired this week as I have been fundraising for MS awareness week! Of course I will be tired. I am excited about the amount I have raised and spent lots of spare time making cakes. This weekend we are having a bit of a 'do' and will be fundraising again from Saturday afternoon. I know in order to get through the day I will need to have a nap/rest around late morning/lunchtime. It is hard for me to do this as I am like a kid when it comes to entertaining, but on the plus side my husband is the adult and makes me go to bed for an hour! I know in the long run this will be better for me even if at the time I am thinking 'do I have to'

Geoff: It is much easier looking back on this process than trying to sort it out. But it has made a big change - both to what I can achieve and to my self esteem (both things I would have said might suffer by following this route)

Michelle - OT: Sounds like you have been busy, Debbie. As you say, taking a rest can often assist you in getting through a busy day. I think a lot of us don't naturally feel OK with having a daytime sleep, but once we can see the benefits it

make it easier to do it the next time. All these changes to your normal way of doing things are hard to deal with aren't they.

Debbie: Nikki, I could not agree more. Prioritising is definitely the way forward! Life is too short and if you can get someone else to do things for you, don't see it as defeat, accept it graciously and think of all the great things you will be able to do instead.

I learnt the hard way and felt great cleaning my house when my cleaner was sick. I thought, I can do this, I don't need a cleaner. Next day I was knackered and suffered the rest of the week - so never again. When my mother in law then offered to come over and do my ironing, I was extremely grateful and it meant I could cook us all a fab meal, which was more fun and not as tiring!

Michelle, you are so right - changes to your normal way of doing things are hard to deal with but once you get over this hurdle (and it did really take me some time to do this) and you see the benefit you do ask yourself why you did not do this sooner.

I now tell everyone MS or not life is too short to do jobs that other people can do for you. Go out and have fun!

Nikki - MS nurse: Well done, Debbie. It is the important things like this that make sense. If someone offers help - definitely accept it. No way is it giving in, it is accommodating the MS and moving forward. Your quality of life will be so much better for you and the rest of the family

Tina S: Very helpful reading all these comments, I have a cleaner, an ironing lady and my partner always does the shopping. It has taken years to accept that it is more beneficial to let others do these chores so I can get on with important things. I can't do these things, so I accept that someone else can and is glad of the work

Frank: My wife, Jennifer, has reached the stage where walking any distance at all is a real struggle. When the fatigue is so great what do you suggest for aerobic exercise?

Michelle - OT: One of the most important things to remember with exercise, in relation to managing MS, is doing anything is better than nothing. So if Jennifer only walks a short distance then rests, that will still be beneficial. Or doing some chair based exercise - as in the MS trust exercise DVD - will be useful. She will still get her heart pumping and that is what we are after, even if only for a short time. The other thing that a lot of people are now finding useful and fun is using a Wii - this can get you moving at home and you can pause it when you need a break.

Frank: Thanks. We bought a vibration plate exercise machine which I reckon helped a lot. It's difficult to keep using it over the months though... and we've stopped. I felt that this would tone muscles without needing the energy from Jennifer. It's difficult to associate managing fatigue with making Jennifer more tired. I'd also considered using electrical stimulus (slimming pads etc) to exercise the muscles. Would this help?

Nikki - MS nurse: In all areas you can now get exercise on prescription at local council run gyms which means a 12 week exercise programme with a mentor working with you. We have seen good results with this in Stoke

Michelle - OT: To be honest, Frank, whilst the electrical pads etc may help with muscle tone, they will not assist in maintaining fitness, so you could be putting in money and time without the benefits you want. For fitness and to assist with fatigue, it's better for Jennifer to do small amounts of activity.

Frank: One very effective exercise was attending Riding for the Disabled sessions. Bouncing about on the back of a horse stimulated lots of muscle reaction and was good fun as well. I found that there was a huge difference between walking and balance etc at the start of the session and what was achievable at the end. Great social experience as well.

Nikki - MS nurse: I agree with Michelle, exercise is any activity that involves physical movements and effort

Frank: This has been very interesting. Jennifer is muttering about slave drivers etc as we've discussed a new (but very slow and steady) exercise regime. Please tell me that doing the dishes and hoovering is exercise!

In broad terms it looks like the advice is to try to keep exercising but to build in recovery sleeps/breaks at regular intervals. Some seem to use rest as a way of preparing for a busy day... Can we put energy in the bank like this? I've tended to schedule quiet days after busy ones

Geoff: I find disguising exercise as something else helps. Someone mentioned walking the dog. If it's going for a nice stroll that's fine - call it taking exercise and my mind resists the idea! :)

Michelle - OT: I would say that dishes and hoovering are definitely exercise! Some people find 'banking energy' useful, others prefer your way of busy/quiet days - it will just be what works for you.

Nikki - MS nurse: Frank, of course this is exercise! Working within your limitations is really important. Organising a relaxing day after a busy day, helps the body recover quicker and allows some reflection. If things went well, then you have learnt from the experience, if not re-adjust

Cally: I was diagnosed with relapsing remitting MS in summer 2008 and my symptoms include fatigue, leg pain, spasms, balance issues, weakness and dizziness. Gradually I have found working full time difficult and started to work from home more, but realistically I have struggled to have the energy to give my all to my job full time. I fell pregnant in November 2009 and my baby is due in July 2010. I have been signed off work throughout my pregnancy to date due to various complications (MS relapse included) and now can't differentiate MS fatigue with pregnancy fatigue albeit it feels like a double whammy!

I am concerned about giving birth. My general weakness and tiredness make me concerned about giving birth naturally and feel I want to elect for a caesarean. I am worried that the doctors won't be supportive as in Scotland elective caesareans are more difficult to agree I believe. I am also worried about my ability to cope with the baby once it is born as my fatigue is all consuming. Any thoughts and tips would be most welcome. Thanks

Nikki - MS nurse: Congratulations! You need to work with your health professionals on this. Remember, you are in charge and only through discussions, questions and answers can you make an informed decision on the birth and ongoing care of your baby.

Frank: Cally, we had our son 24 years ago (aaarrgh)... Jennifer managed well at the birth and reckons that the epidural was better than sliced bread. I'd say in hindsight that the hormonal changes as she approached her labour date were beneficial at the time. She looked and acted healthier than she had for years. I agree that looking after the little monster/darling was an issue and I suggest you start priming relatives etc now to give you some time to yourself. The only other point is they seem to get more expensive as they get older, so try to ensure you have the support to really enjoy the early years. Life changing in a very positive way...

Michelle - OT: Same from me, Cally. You need some discussions with both your MS health professionals and those who are caring for you during pregnancy. Also, have you tried some of the 'mum' chat rooms, such as NetMums? They have loads of different forums, so you might gain some support there from other people experiencing similar issues. Really hope you can make the choices that will be best for you and your baby.

Simon - MS Trust: There is an MS Trust factsheet on pregnancy and parenthood and we've also run a blog by a woman with MS that followed her through her pregnancy and, so far, the first year of her son's life

Michelle - OT: That sounds like it could be useful for you, Cally.

Cally: Thanks. I have the MS factsheet already, which is great. I will try the blog too, which I haven't yet looked at. And of course stay close my neurologist and obstetrician re joining up to make the best decisions. All very nerve wracking but exciting!

Georgia: I have had relapsing remitting MS for 12 years and now have an energetic, gorgeous son, Sam! I coped well with being pregnant but his first year was tough, as it is for any new mum! Support, support, support from everyone is the key. The continued journey in parenthood is amazing. The MS gets in the way at times but is overridden by the good times.

Dave: We have two grandchildren who really help with brightening up our day, but when they go home at weekend, it's time for forty winks in the chair

Nikki - MS nurse: As Georgia says, support is really vital. Never turn it down, and if you don't ask... Taking control feels good and the more information you have the more power!

Georgia: I find it easier to get support for my baby (now toddler) as he's so important and relies on me (and my husband), whereas I haven't found it easy to get the right support for me all the time! My husband is great and does cooking and housework when around but he works so very hard. I'm not back at work yet and am a bit anxious (Sam is in nursery two days a week)

Alison M: Hi Georgia. When my kids were toddlers (they are 5 and 7 now) I would rest when they were in nursery or napping. Sometimes we rush around and think we can do loads while they are out of the way, while true, our needs are more important. It's great that your hubby is helpful when around, I just

make sure I do simple healthy food, I don't iron! (unless linen or cotton so not much) and I say to myself each day, what is essential today and what can be deferred to another day?

Carol: I was diagnosed two years ago now and work full time, 37.5 hours a week, as a nurse. I find the unpredictability of fatigue really bothersome. I have had support in the beginning from my local service OT and the best advice then and now is to pace myself. Easier said than done some days. My local MS nurse is also great, but any tips from fellow sufferers would be gratefully received.

Nikki - MS nurse: Everyone I suppose has bad days - especially in this line of work. You work full time, which is difficult for anyone, so I think you do remarkably well. You should definitely reward yourself and often with treats like a pampering day. Pacing is all about knowing the boundaries, delegating what YOU don't need to do and being organised in what you do do.

Carol: Thanks. Compromise is the key word I agree, but easier said than done when I have always been a do-er! My partner is great and helps a lot, and my teenager son is also doing his bit. I used to get to yoga once a week which I found helped but recently doing the class in an evening after a days work is a no no sadly. At 54, I think myself lucky that this bloody disease did not come along earlier

Nikki - MS nurse: Have you tried the exercise DVD from the MS Trust? Recently a chap in Stafford found this so helpful and he has never done any exercise at all, he said. The main aim was helping him feel less fatigued and it seems to be having some effect at least.

Debbie M: I love the cold weather, but the hot weather brings out all the bad symptoms. As a teenager I would sit out in the sun all day. Now I'm under the umbrella, like carol I'm glad the disease came out later. I'm 48 now but that poor little mite diagnosed at four years old was awful

Carol: No, I haven't tried the DVD but now I will get a copy and give it a go. Thanks

Debbie M: Just walked the dog, now I'm shattered but after half an hour will be back on track. I have had MS for ten years but it could be the fact of getting older that means I'm slowing up and forgetting things. But come to think of it, I have always been that way lol

Nikki - MS nurse: Short term memory and concentration problems can be frustrating, cant they? You do have the excuse of having MS, which will affect it! Your coping strategies are fab - having a good laugh about it!

Debbie M: Yes, having a sense of humour is important when dealing with MS. Its like when they say MS 'patient' when they should say 'patience', as you really need that too lol

The joy of having three teenagers is that when I go out to the freezer in the garage and stand there thinking 'what did I come out for?' I can always hear one of the kids shout out 'CHIPS'!

Lizzie: Hello everyone - first of all thanks for running this chat. I am 33 and was diagnosed four years ago. I started noticing fatigue a couple of years ago when I found it really hard to motivate myself and felt so tired all the time. My neurologist prescribed Modiodal (I live in Spain I don't know if that's the same in the UK). Recently I think its effects are wearing off so the neurologist suggested doubling the dose. I have read the suggestions above and think there is more I can do to manage my fatigue so will try that first.

I was wondering if there is a connection between mood swings and fatigue - I have been finding that my thoughts have become slightly irrational and I think this may be connected to the fatigue - does that happen?

Simon - MS Trust: Modiodal is available in the UK as modafinil or Provigil - a drug used to treat excessive sleepiness associated with narcolepsy. It can be useful for some people with MS related fatigue

Nikki - MS nurse: With modafinil sometimes a drug holiday can work. Come gradually off it and have about four to six weeks break and re-commence it again slowly. MS causes mood swings, so can some medications too. If you have fatigue, this also will affect the mood. So it's multiple factors really which need assessing and action

Michelle - OT: Lizzie, glad to hear you have found some of the previous discussion useful. Whilst there isn't a documented link between irrational thoughts and fatigue, when any of us are feeling tired it can cause us to be irrational. Often the frustration that goes with MS can add to this. I would keep an eye on it and if it becomes difficult, then have a word with your GP.

Lizzie: I will try a drug holiday (sounds like a long weekend in Amsterdam :-)). Seriously though, thank you.

Fenella: I have to have a nap middle of the day because of fatigue, which I can cope with, but I keep getting fatigue in my jaw whilst eating. I eat slowly and have to stop and have breaks. Is there anything else I can do? I don't fancy living on soup.

Jane: I'd not heard of fatigue when eating. That must be difficult. I seem to be a two days in one sort of person - up, do a bit, nap, up again, do a bit more, bed.

Debbie M: I have that problem sometimes - if I'm tired and I am eating I sometimes forget how to swallow. I used to panic but I can cope with it now

Fenella: It's difficult when I go for meal (don't go often). I can't walk too far (I can handle), constantly buzzing (I can handle), feeling a divvy (I can handle) but I do like to eat food.

Nikki - MS nurse: Eating should be a joyous occasion! So eating a meal when you can enjoy it is important. If preparation is making you more fatigue, perhaps preparing well in advance might help. The swallowing problems may need assessing by a speech therapist. There are tips for managing in Michelle's MS Trust book on fatigue (*Living with fatigue*).

Michelle - OT: I agree with regard to an assessment by a speech therapist. Sometimes simple techniques with regard to head position etc can make a difference. If eating out is one of your pleasures, then it is important that everything possible is looked at.

Dave: Good morning. I have flitted through a few of the posts and agree with all that I've read. My wife was diagnosed with MS approximately three years ago and has been off work with depression for two months

She has primary progressive MS, and while she has been off work, her sleep pattern varies with the weather. She can be up until the early hours, going to bed at sometimes two or three o'clock!

Nikki - MS nurse: I think it's important to try to adjust your wife's body clock back normal if this is possible. Sleeping at night, perhaps with a short power nap in the afternoon?

Dave: Just lately my wife has thrown herself into tidying up the garden. The boys sometimes help, but sometimes you feel like you are interfering. What doesn't help is as well as the MS in her upper spine, she suffers from spondylosis in her lower spine and her walking becomes laboured, sometimes looking like she has had a stroke. Cat-naps little and often help with her fatigue

Carrie: I had to finish work this year, mainly because of my fatigue. I know everyone can feel this in different ways. For me the fatigue usually hits about three or four hours after getting up in the morning, which makes a very short day. If I get up, say, at 8am, I'm shattered by midday. I usually go to bed for a few hours. If I can sleep, it is a huge relief and I'm able to function reasonably for a few hours before the fatigue hits again. If I can't sleep during the day, I am up and down, resting and getting up all afternoon. I try and get eight or nine hours sleep at night (amitriptyline helps) but if I don't get this, I am even more exhausted the next day

I feel frustrated that fatigue is often not recognised as such a debilitating symptom of MS. I have been turned down for Employment and Support Allowance (ESA) as it is mainly marked on mobility issues (although I am appealing). I don't know about others, but I find that things that are supposed to help with fatigue and stop you feeling it, make me feel worse eg modafinil, strong coffee, certain herbal treatments

I know that exercise is a must, but I have to plan to do it when I can go to bed afterwards, as even a short walk can make me feel exhausted.

I am so glad that fatigue is being discussed here.

Samir: I used to fall asleep at my desk when I last worked and thought that narcolepsy was a symptom of MS

Nikki - MS nurse: Carrie, fatigue, as you say, can be totally disabling and can affect people as badly as poor mobility. The more information you can provide ESA about how fatigue affects you and what it prevents you from doing will help them make a decision. Modafinil and amantadine seem to work in some people

but only a small proportion. Exercise as you say has been shown to help most of all.

Michelle - OT: The difficulty with some of the caffeine/herbal treatments is that they give you a quick high but then a harder low. I am thinking that if you have to go to bed after exercise you may be still doing too much, you may find it useful to do smaller amounts/less strenuous activity but do it more frequently.

Frank: Carrie, can I suggest that you detail the mobility issues you face each day when you are fatigued. Benefit claimants spend too much time detailing what they can do and not what they can't. It's understandable but self defeating as far as claiming is concerned

Fiona: I have had mild MS for over 25 years and am now 48. In the last couple of years I have definitely got more tired and had weakness of the right leg. I recently started on tizanidine as I was having a spasm in my foot, which can keep me awake at night. The foot seems fine through day. I also had three doses of intravenous steroids to see if that would help with the leg and foot as there was some inflammation shown on the brain scan. I can't say I have seen any difference so far. Has anyone else had that experience? Basically my frustration now is the foot and leg weakness as I play golf and walk dogs. I did listen to a radio programme and that made me get my head out of the sand as the lady just said MS is progressive whether you are benign or not. Now that I have got my head around that I feel a bit easier, albeit I still try to do too much hence some of my fatigue.

Edward: I'm new to chat rooms - never had the energy to visit one before, so I hope that this isn't inappropriate. Has anyone tried Chinese medicine to help to keep awake? If so, is there anything that you have tried in addition to cordyceps, hericium, lingzhe (reishi) and astragalus root?

Alison M: I have had relapsing remitting MS for about 15 years (diagnosed in 1998). I am very lucky as I am on Rebif, but the fatigue is the one symptom I carry ALL the time! I have two small kids and work part time. Is there any natural things, medical or nutritionally, that can help please?

Edward: I know that the MS Trust and Society have published dietary guidelines but I have found that some Chinese medicines and acupuncture help a bit. I asked earlier if anyone else has used anything other than the ones I know about but nobody has replied so I guess that no-one does!

Marcia: I had Reiki for quite sometime and found that beneficial, Edward

Jin: I've tried relaxation things - massage, reflexology - (which seemed to help), but not any supplements. I too originally went for the caffeine hit to try and counter tiredness and gave myself headaches and ultimately the need to take a whole day off in bed to rebalance myself

Nikki - MS nurse: There is some excellent dietary advice available but to be honest, with MS it is a well balanced nutritional diet, low in saturated fats and supplemented with omega 3. Also the latest factsheet on vitamin D from the MS Trust. Carbohydrates and fatty foods can tire you more. Fresh fruit is high in natural energy and will help through exercising.

Edward: Chinese mushrooms seem to regulate the immune system although they haven't been approved by NICE or subjected to evidence-based western research. Cordyceps is claimed to improve 'endurance' and was used in the training of Olympic contestants a few years ago and the coach said it was responsible for the nine gold medals won by previously unknown athletes. Hericium is used in Japan to help regenerate nerves in Alzheimer's sufferers and has been shown to regenerate myelin in damaged nerves. I know that this isn't the case with MS since it is only the myelin not the nerve fibres which is degenerated. Lingzhi (reishi) is a general health supplement. This is getting a bit long so I'll stop now

Has anybody tried any other Chinese supplements?

Nikki - MS nurse: Thanks Edward. As an MS professional, we don't recommend any Chinese herbal remedies. The medicines would need good research evidence before recommendation. They may also interact with prescribed medicines, so certainly needs researching first.

Nigel: Tiredness has now become the one single element of having MS that I loathe the most. I can almost accept the prospect of probably being confined to a wheelchair sooner rather than later, the continence issues, the electric shocks, pain and other annoying elements of the ailment but tiredness is destroying everything.

I struggle to get to sleep (last meds of day are amitriptyline, codeine phosphate, lyrical, diazepam, baclofen and a few others), as the legs they are a zapping and feel like they're on fire (we know the feelings don't we folk), and watch TV or listen to music before I drop off.

Once I go to sleep, I have found over the last 18 months or so that I don't wake up. I can 'switch off' for up to 12 hours and rousing me is akin to having come out of theatre having had a general anaesthetic. If I am awoken by a third party I experience a complete melt down of the thought processes and am sick. I see flashing blue 'shocks' in the head, tingling in my face and I have limited co-ordination of limbs.

Getting up for an appointment (only medical these days), is a nightmare as I can sleep through two alarm clocks (buzzer and radio set at distortion level), and five mobile phones, the two loudest of which are under the pillows and could awake the dead.

On these days (they predominate), I feel listless all day or days now. The simplest of tasks, the making of the essential cup of tea in the morning or popping a slice of toast in, become almost impossible tasks.

I might not be able to work but I have scintillating friends and am involved in many activities that are mentally stimulating. Despite all this I can sit like a cabbage for hours nodding in and out of sleep. I see images of care homes where the elderly sit in chairs around the room drifting in and out of consciousness. Do I have this life changing spectre to live with till I die?

By the way, I do try and follow all the tips that I have learnt from my MS Nurse but nothing seems to work.

Once in the un-dead world it takes a good couple of hours before my brain feels like anything other than semolina, a food item that when served as a pudding has no possible use. My brain, is it a bowl of semolina?

Angela: Do you really need all those medicines? I myself was on a whole raft of things and would constantly have woolly head. Since stopping many drugs, the woolly head, if not completely gone, is much improved for the majority of the time.

Marcia: I have recently been diagnosed with B12 deficiency. Taking the B12 tablets has definitely helped in all sorts of ways and I now feel it would be a good idea if all with MS were given B12 tablets

Debbie: I too have B12 deficiency and iron deficiency and every three months have a B12 injection and iron transfusion. It really does make a difference and feel like recharging the batteries! I feel myself winding down just before it is due and my husband says he can always tell when I have had these done as I am buzzing for a few days!

Marcia: I refused the injections for B12, as I didn't like the sound of side effects. The tablets have been very good, I just I have to buy them myself from internet!

Frank: How can you tell if you are B12 deficient? Symptoms look to me like 'normal' MS?

Marcia: Blood tests, Frank

Debbie: I do not seem to have any side effects form the injections or infusions. My symptoms were hair falling out, tiredness and anaemia, all detected by a simple blood test.

Marcia: I get reactions to medications like thyroxin and set off primary progressive MS by flu jab, so couldn't chance B12 injections

Andrew: I was diagnosed with primary progressive MS last year. The change to life has been dramatic in terms of lifestyle. The area which I have found most beneficial has been working with a neuropsychologist to change my way of thinking and approach to everyday issues. Pressure (positive or negative), stress, frustration etc all have a negative effect on my symptoms and being able to change my mind set to remove these can show positive results within minutes eg fastening buttons on my shirt, tying shoes laces, different ways to prepare meals. Forward planning, regular healthy eating, drinking plenty of water - all have an effect but not in isolation. It took me four months to assess whether amantadine had any effect at all - it does with primary fatigue - but I only realised this when all the other aspects fatigue management were in place.

I am not looking forward to summer as when the ambient temperature reaches 21 degrees fatigue really sets in, has anyone any thoughts on combating heat induced fatigue?

Simon - MS Trust: A few years back we had an article on staying cool with MS in our Open Door newsletter

Michelle - OT: Hi Andrew, just using simple techniques to keep cool can prevent heat induced fatigue. Lots of cold drinks, if possible get some sweat bands (very eighties!) and really soak them in icy water or put them in the freezer and then put them on. Similarly, in the house, put a wet towel at the back of you neck. You can try cooling jackets, that is more expensive and bulky, but the MS Trust can give you more info if you want. If you are in work, under the disability discrimination act you have a right to fans and even air conditioning, as it is recognised that you need these things to manage your MS.

Nikki - MS nurse: Preventing your body temperature from increasing even by small adjustments is important for lots of people with MS. Some use the usual methods, cool drinks, keeping out of direct sun, cotton clothing, a hat for protection, etc. There are also cooling body suits. Not sure how many people use these but they may help. Air conditioning in the car is vital.

Nigel: Andrew, should we ever get anything that vaguely approaches summer, do what I do, don't go out. Cold drinks in the fridge and get one of those cold air blowers as they are quite effective and affordable.

Just accept that you will never be one of those people who just lie around on sun loungers all day. You have MS and we live indoors and part of our contract with the disease is that at 21c, we turn off

Simon - MS Trust: We found it helped publishing the article on keeping cool. As soon as we'd done that we had one of the coldest, most MS-friendly summers for years!

Carol P: Is that right that under the DDA you can have air conditioning at work? That would be great

I was diagnosed last June and was off work for five months, but am now back full-time since February, so there is hope! It used to take me half hour from getting up and getting out the door for work before I was ill. When I came out of hospital and had to get back to work I found it took half hour before I felt I could even move - let alone get out of bed. Things do improve, try to keep positive about what you can do, not what you can't.

Nikki - MS nurse: It is certainly worth applying for a work based assessment. Disability Employment Advisors (DEA), who are based at your local job centre, will come out to work to assess your individual needs.

Carol P: Thanks Nikki - I will ask at work

Michelle - OT: Yes, under the DDA, your employer must look at 'reasonable adjustments' for you to maintain your work role. Air conditioning could be something they look at. This might not be possible in all work areas but then fans and cold water machines should be possible in most environments. Contact your local access to work advisor for more info. I will see if I can post the link.

Carol P: In my office there is a male colleague who also has MS and our office gets very hot in the summer

Michelle - OT: At the bottom of the transcript there is a link to Access to Work, who will assess your needs in work. I have worked really closely with them previously with some good results.

Simon - MS Trust:

Mentioning Open Door, the MS Trust's free quarterly newsletter - if anyone would like to consider writing about their experiences of living with fatigue, please feel free to contact us on info@mstrust.org.uk

Sue Ronaldson, who works for Harrogate and District NHS Foundation Trust also contacted us to ask if anyone would like to contact her about the impact of fatigue on sexuality and sexual interest, frequency, for an article she is writing. If so, email sue.ronaldson@hdfnhs.uk

Finally, The MS Trust working on a project looking at sexuality and men with MS. We are asking men affected by MS to complete a short, anonymous survey to help us with this. You can see more at www.mstrust.org.uk/men. Enough adverts, back to the chat

Willie: I also work full time in a great environment and have quite an issue with fatigue. I generally sleep fairly well - certainly not any worse than pre diagnosis.

I take some downtime at lunch time and sleep for 15 minutes but still find that I am totally exhausted by the end of the day and wobble when I walk at this point. There are references to acetyl I-carnitine and alpha lipoic acid having great benefits for fatigue. There are some side effects I am aware.

I was diagnosed in December last year and have a good knowledge base on my condition - relapsing remitting MS

Simon - MS Trust: There are two papers looking at lipoic acid and MS in human. Both refer to small trials (one study 38 people, can't see numbers mentioned on the other) and looked at its role on MS in general rather than at fatigue. Seems to have a positive antioxidant effect, but no indication in the research of the therapeutic value

Willie: The reference came from the MS Society Forum - there seems to be some good feedback but will watch. Am at the point of watching but interested

Simon - MS Trust: Again a handful of papers looking at acetyl I-carnitine (or carnitine or levocarnitine). Also again mostly small studies. A Cochrane review concludes "There is insufficient evidence that carnitine for the treatment of MS-related fatigue offers a therapeutic advantage over placebo or active comparators" - this is possibly due to the small numbers of participants in the published trials. These trials do report an effect on fatigue. One study of 36 people says it is "better tolerated and more effective than amantadine for the treatment of MS-related fatigue". Another study as an add on to disease modifying drugs says "decreased fatigue intensity, especially in patients treated with cyclophosphamide and interferon beta."

Simon - MS Trust: I'll add the references to the papers at the bottom of the transcript

Carrie: I have just ordered some alpha lipoic acid and acetyl I-carnitine, as someone suggested this on the MS Society chatroom. It will be interesting to see if it has any benefit.

Willie: My thing is not to rush into too many things. I am on LDN and watching and waiting - there could be benefits but then again.

Simon - MS Trust: That seems sensible, Willie. If you try things one at a time, you can tell which one is working. Also wise to ignore any hype (for or against) and monitor how something works for you. If it works, great, keep going. If it doesn't, well, remember that not everything works for everyone and try something else

Willie: There are subtle differences but watching and waiting, thanks Simon

Kevin: I have just been diagnosed - in July last year - with primary progressive MS. I would like to ask if anyone has found any help from high energy drinks as I am not looking forward to this summer's possible heat and I am also trying to maintain a level of my mobility with regular exercise. Thanks

Frank: We found there was a significant impact on bladder control - high in caffeine I think. I reckon water or diluted juice is best.

Andrew: I've no experience with high energy drinks but regular balanced eating with plenty of fruit. Drinking plenty of water had a dramatic effect on energy levels very quickly

Kirstie: I've had chronic fatigue since I was 16 after a bad case of glandular fever. I am now 20 and still suffer badly from both. I wonder if there are other illnesses with the same symptoms, or is it a sure fire thing that it is chronic fatigue syndrome (CFS)?

Nikki - MS nurse: When you say you still suffer from both - both what?

Kirstie: Chronic fatigue and glandular fever is still in my system

Nikki - MS nurse: Are there other symptoms with the chronic fatigue?

Kirstie: I'm not sure most do fall into the CFS category but my glands are almost always massively enlarged and I feel like my local GP has not given me all options or info they could have. I get dizzy, I have really bad stomach pains, I get confused easily, there's a lot really. Is there really nothing that can be prescribed for CFS?

Simon - MS Trust: Whilst there is an overlap in some of the general principles of fatigue management, if your symptoms are more like chronic fatigue syndrome rather than MS related fatigue, it might be worth talking to Action For ME, who are a CFS charity

Nikki - MS nurse: Do you have a specialist or GP who can try to help with your CFS? I imagine it's as difficult to treat and manage as MS fatigue sometimes is. Whilst some of the MS support and literature can be helpful, I really am not qualified to advise you.

Chris: What do people feel about amantadine?

Marcia: My GP will not give amantadine says it's for Parkinson's disease type fatigue

Nikki - MS nurse: Amantadine, as your GP says, was initially used for Parkinson's disease but has been researched in MS. It might be worth taking some literature to your GP to discuss it. Usually if a health care professional (nurse, doctor) recommends it, the GP is happy to use it for a trial period. It will need to be monitored and the side effects looked into before making that decision.

Marcia: Sorry Nikki, my MS nurse contacted him for me and he still refused

Simon - MS Trust: Marcia, amantadine is mentioned in the NICE MS guidelines. Maybe this can add weight to your request. The mention is hardly a glowing recommendation, but it is proof that it is a recognised treatment for MS fatigue. The entry says "A medicine called amantadine may help a little at a dose of 200mg a day, but the benefits are likely to be small." (You can download the guideline from the MS Trust website - the quote is from the people with MS version)

Marcia: Thanks Simon, but I think the stage I'm at now the B12 is helping more than anything

Andrew: Amantadine has a positive effect for me with primary fatigue, but its effects are subtle. It needs to be used in conjunction with your overall fatigue management plan, it certainly isn't something I've seen to have an instant or dramatic effect

Michelle - OT: I agree with Andrew's comments. The potential benefits of medications are optimised when used in conjunction with an overall plan which includes exercise and pacing etc.

Andrew: I was prescribed amantadine by a neurological rehabilitation consultant. Could a neurologist prescribe this? Do MS nurses have prescribing powers?

Nikki - MS nurse: The nurses at Stoke prescribe but we sadly don't have a prescribing budget. This is up to the Primary Care Trust. Generally, if we recommend something and have good evidence for using it and we are prepared to monitor someone's progress, there are not too many problems.

Frank: We've found that mental effort can be very tiring. Trying to concentrate on something (like the activity on this chatroom) seems to drain energy at an alarming rate. Do these brain trainer games have any effect on getting the brain less fragile?

Simon - MS Trust: Frank, there is a website we've set up called StayingSmart which looks at ways of coping with cognitive problems - memory, concentration, attention span, etc - all of which can be worse if you are fatigued. The site has tips from visitors to the site and information about different aspects of these symptoms

Nikki - MS nurse: Frank, there was a good TV programme on last week indicating that brain trainer games only help because they help you to get better

at doing them! Our psychological therapists do recommend doing puzzles, crossword etc, to help with cognition (short term memory, concentration...) and fatigue

Simon - MS Trust: This may have been the programme Bang Goes The Theory on the BBC. The report was based on a study recently published in the journal Nature.

Theresa: I was just wondering why my head keeps nodding. It's been like it since Sunday gone. Is it down to fatigue? I've had MS now for 12 years and have had this on the odd occasion, but not for so long.

Nikki - MS nurse: When you say your head keeps nodding, can you describe this?

Theresa: It's just a constant nodding, you know, like ornamental dogs in the back of car windows. I know it's a weird way of describing it. Also when a fizzy drink fizzes up that's how my spine feels.

Nikki - MS nurse: The nodding head sounds a little unusual and I think an assessment would be the best way forward. Somebody to physically assess the problem. Can you see somebody in your area? The fizzing, however, is more common and is called L'hermitte's sign. It's often caused by inflammation of the cervical spine and causes electric shock type sensations down the spine, into the arms sometimes and even legs sometimes.

Michelle - OT: Doesn't sound fatigue based. It's now Wednesday, so as with any new symptoms I would contact either your MS nurse or other health professional

Theresa: I don't understand. Physical assessment by whom - my GP or somebody else?

Nikki - MS nurse: Do you have an MS nurse to contact? If not, your GP would be useful

Michelle - OT: Your GP initially, if he has concerns he might ask the neurologist

Theresa: Thank you, I have got to see my GP today and will go from there. I spoke to the MS nurse and she said I might have a problem with my back so she said to contact my GP - but my back is fine - and to phone her to let her know if it is MS related. Thank you

Nikki - MS nurse: Hope that goes well, Theresa.

Ellie: Does anyone know a drug that helps fatigue which does not keep you awake at night? I value my sleep so much I am scared to try anything suggested. Just getting over major abdominal surgery so fatigue is worse than usual

Nikki - MS nurse: If amantadine helps it can be useful but it does not help everyone. If taken early morning and if required twice a day, the second does is best taken before 2pm to ensure your night time sleep is not affected.

Ellie: Thanks. I have never taken anything for fatigue, and have had MS for over 20 years. Trouble is I find it hits me like a train at 4.30 every day. Whatever I have been doing or not doing I am useless after that time

Debra: Once I've done the basic household chores, I have the MS 'bear-hug' pain around my ribs - the banding. It is usually only about mid-morning at this time and I feel a bit guilty resting so carry on doing various things eg on the computer - again in a sitting position which isn't good for the banding pain. After lunch, I do have a solid sleep as, by then, I'm exhausted. What I would like to know is, should I take a break mid-morning and then carry on with things after lunch? Also, and perhaps more importantly, I don't understand how people with MS in wheelchairs are always in the sitting position. I would find it easier to lay prone, as this is the only way the pain is relieved

Nikki - MS nurse: As you know, everyone is different but it sounds like a mid-morning break might suit you. It is recognising when you are at your best/worst, possibly completing a bit of a diary to assess it, then monitoring what works and adapting if necessary. Things can change too, so it's re-adjusting to those changes. It's important to change positioning regularly. Pain can be made worse in certain positions and exercise and movement even from a chair is good advice.

Andrew: I have primary progressive MS - symptoms and fatigue have continuously declined over the period. Fatigue used to set in after a full day on the fells following foxhounds on foot. When after coming back down, I was slightly flat footed in my right leg. Now fatigue sets in after getting up, showered shaved and dressed. Does fatigue keep appearing after less and less activity? Where can it end?

Simon - MS Trust: Whilst Nikki is working on her answer to you, you may be interested to know that later in the year the MS Trust will be publishing a new book called Primary Progressive MS Exposed, looking at this particular type of MS. No date for this yet, just keep an eye on the website or Open Door

Nikki - MS nurse: Andrew, yes your body becomes out of condition/deconditioned and therefore this makes you more fatigued. Exercise or activity has been demonstrated through research to be beneficial and can reduce motor fatigue and can significantly improve your levels of fatigue. Becoming more fit really will help.

Carla: I was diagnosed in 2005 with relapsing remitting MS and I'm a professional fatigue-ist with the attention span of a gnat. I don't/can't pace myself and regularly run myself into the ground. I have B12 jabs and to date the only improvement has been stronger nails and my hair is lovely. I do find Red Bull very handy if I need to be fully compos mentis for 20 minutes or so. I also have major spinal problems-hence the stubbornness.

Nikki - MS nurse: What is the biggest factor which stops you from pacing yourself do you think?

Carla: I have degenerative disc disease as well, so have always tended to get as much done as possible when I'm able so when the MS arrived it felt like I'd be giving up. I've got the - 'it feels like I have ants crawling up my legs thing' today

Alison: Just popping in briefly - has anyone any thoughts on homeopathic remedies for fatigue?

Simon - MS Trust: No one's mentioned homoeopathy yet, though Edward earlier had thoughts on Chinese herbs. Have you tried homoeopathy for fatigue?

Carla: All I've been told is never use echinacea?

Michelle - OT: The evidence for homeopathic medicine is limited. Whilst I would never put somebody off trying something they think is potentially useful, I would always keep this point in mind. Some areas do have access to homeopathic clinics but these are limited, so in order to get to see a homeopathic practitioner you will be paying quite a lot of money, and then the treatments are often expensive - this is something to consider also. I wouldn't recommend buying medication over the internet.

Carla: Is it OK for my partner to come on here as he has loads of questions?

Simon - MS Trust: Yes, the session is for anyone with questions about MS fatigue, whether they have it themselves or not

Ron: Hello, it's Ron here. I am Carla's hubby to be.

Simon - MS Trust: Hi Ron. What questions do you have about fatigue and MS?

Ron: I am new to this and so any information would be helpful

Simon - MS Trust: How does Carla's fatigue affect you?

Ron: It doesn't really affect me as such. We walk the dog but I have noticed we don't walk as far as we once did. This I understand but wonder should I be looking out for more things or helping Carla in any way I might not have thought about?

Michelle - OT: Hi Ron. One of the key things for Carla in managing her fatigue is being able to communicate what will be helpful with those around her - so it's great to see that you are open to ideas. Sit down and have a chat about it. It might be she could do with you taking on some tasks, or maybe she needs you to push her into doing more exercise. She will know!

Ron: Thanks Michelle, I will do that. I think the world of Carla and will do all I can. I just think sometimes I would like to where I need to ask somebody something as it comes up. Now I know you're all here I might be able to that.

Simon - MS Trust: The chatroom is a one day event, but the transcript will be posted at the Chatrooms page in a week or so. We also have a book called *Living with fatigue* (written by Michelle). And of course, the MS Trust Info Service is available to anyone affected by MS - whether they have it themselves or know someone who does.

Ron: Thank you Simon. If I was to join your site as a full member would there be a chat sight on it most the time? It's just I am one of the people that think, Oh I need to ask somebody about that and then it goes clean out of my head later on.

Simon - MS Trust: We don't have an ongoing chat, but there are discussion lists that give you a place to pitch questions. Loads out there - the details of the MS People UK group are at the end of the transcript.

Ron: Thank you for that Simon. You have been of more help then you know. I hope I can be a regular on your site. I'll just go and make Carla a coffee and talk later.

Nessie: I've been following the comments and have found them interesting, even noticed a brief appearance by my hubby, bless him.

It's hard sometimes to distinguish the tiredness from normal or MS related. I tend to know when I'm feeling at my worse, when everything is a bind or takes a lot of energy just to do a normal day's activities. Up till recently I worked full time but have gone off with depression or being physiologically vulnerable (which I like). Today I'm having what I call a punch drunk day, when I feel like I'm at sea. Yes things do seem to be tiring me out and I'm trying very hard to pace myself.

Until now I've coped fairly well, but just don't seem to be getting forward. I've chatted to my nurses who are really helpful and my therapist is a good listener.

I now I've rambled on but I'm sure that this is seen as something some of us will go through but if there are any new ideas out there which might help I'll try anything,

I have a saying that my meter has run out and I need 50p to recharge it. I just think at the moment I've run out of 50 pences

We all do well with how we all cope with whatever we go through and these chatrooms are invaluable as they make you realise you are not on your own. I have primary progressive MS and take gabapentin for my dancing leg (nerve pain and twitching especially at night).

Sorry I've gone on quite a bit

Michelle - OT: Thanks for your comments, Nessie. It is good to know that people find the chatrooms useful. I just think from talking to people with MS that fatigue can be such an isolating issue to live with. So through the chatroom it is good to know there are other people out there struggling sometimes and winning sometimes just like you.

Nessie: Although at the moment it seems that I'm taking a long time to win, I'm a lot better now than I was but still having off days. It's when I have days like this when I feel drunk, which my doctor and MS nurses say is connected to my MS, that I think I used to be able to do as much as I did and now can't. I get very frustrated. Being patient and giving it time is something I don't do lol.

But I'm trying very hard to do that now. I think as well it's the reassurance from others telling you that it is normal to feel like this and to give it time.

My occupational health adviser on a recent visit has said I'm fit for work but just need help to get past this hurdle, which I'm doing. Sometimes though, it doesn't feel like I'm getting anywhere, but then I feel, yes I am winning. I know I'll get back to work eventually but just feel that it doesn't exist for me at the moment.

Is this normal and am I being too hard on myself? Just wondered if there was anything else I could try. I visit a counsellor through my doctors at the moment.

Michelle - OT: Sounds like you are doing the right things, Nessie, and getting the support you need.

Nessie: It just seems to be taking a long time to settle. Is this normal? They do say it can take a few years at the beginning to adjust, and I've certainly done - although some people might say I do too much still. My hubby is very good and I couldn't manage without him. He just gets frustrated too because he wishes he could do more.

It's helpful to know that I'm doing OK because you do start to feel like you have to give in and that's something I don't want to do. Fatigue can hit people differently but support and help and learning to pace yourself is the best way. It's easy putting it down on paper and telling people but sometimes when you know what you must do it is hard to put it into practice. Is that a normal feeling to have?

Michelle - OT: Managing fatigue, as you know, is a lot about adapting our lifestyles - pacing, delegating, etc. It is difficult for anybody to make lifestyle changes (even those we want to do!), so it is completely understandable that having to make changes due to a condition that you didn't ask for is hard. But keep trying to make small changes and they will add up.

Nessie: Thanks Michelle, that's helped me to understand that I do have to let things add up when taking time to make adjustments. I've got some good friends and family around me.

Lisa: My partner has MS. He was diagnosed three years ago and is 34 now. He gets really tired and I find it difficult to really comprehend just how tired he really is. Is it better for him to just rest/sleep or to try and carry on? Some times I can see he is tired and still walks, or goes out. I think it's better if he rests but he says he would never do anything because he is always tired. Any advice would be great

Ron: I have that worry too. Thank you for asking that as I could not have put that better myself.

Michelle - OT: I can imagine that for you and Ron it is difficult to understand what it is like to experience MS fatigue. I know that when I am working with

somebody who has MS fatigue and am providing advice on techniques for management, I always acknowledge that I can only imagine it and that it is why it is useful to get them to talk about how it feels - because saying 'tired' doesn't really cover it. With regard to pushing through the fatigue or resting, this is a tricky question to answer as situations will be different. If somebody has lassitude fatigue - this is the kind of fatigue that comes on suddenly and is unique to people with MS, where they feel completely and utterly exhausted - people will say it is like somebody has pulled out the plug. Evidence shows a short rest (somewhere quiet) does assist. If however, it is more a feeling of lacking energy and 'tiredness', then doing a small amount and taking a rest may be more beneficial than not participating in events, as then you start to feel like you are missing out too much. Long answer - hope it makes sense!

Nikki - MS nurse: I think it is important that your partners listen to what their body is telling them. Rest is important after any period of activity/exercise and each person has their own limitations. If they go beyond those boundaries and keep on trying to fight the tiredness it may bite back and you and the family may end up paying for that mistake for longer. Work out what is best between you - adjust if necessary. Taking ACTION is better than fighting on - self management is key and even better when done in partnership with those who care.

Frank: As a partner of a tired MS sufferer, I'd recommend using your judgement to differentiate between tired and knackered. It is clear to me from Jennifer's eyes whether she is wiped out and fighting it. I've found it saves problems if I'm firm and insist on an hour's rest whether she wants it or not. We've discussed this when she is fresh and have agreed that this is sensible. An extra shopping trip when too tired leads to near exhaustion. In the past I felt I could identify a clear link between too much exhaustion and the triggering of an attack

If Jennifer is tired but not too much then I try to get her out of bed and into fresh air. If she perks up then we do more..., if not then a lazy wander in the wheelchair and back for a doze

You are in the position to be able to identify the warning signs. Bottom line... discuss this when you are both feeling good and review later after you've had to draw a line either by encouraging action or insisting on rest

Nikki - MS nurse: Sound advice, Frank

Michelle - OT: Great advice, Frank. I think the key is discussing management strategies when you are both fresh and not in the problem situation, when tensions are always a bit high.

Ron: I guess I am lucky as Carla and have a good communication and talk about most things, but I just need to be a little more educated about the whole MS thing. I feel I am doing OK but as a teacher would tell any school child 'could do better' lol. Always willing to learn, me

Nessie: I like your comments, Frank. That's something I'm learning to do to with the help of my hubby.

Simon - MS Trust: The book *MS Explained* is a good introduction to MS, and the A to Z of MS on our website gives a good introduction to a wide range of topics.

Nessie: Just read your replies to Lisa - thanks found that useful. Yes, sometimes it hits you unexpectedly and other times it can be there when you get up. I seem

to function better at night, Always been a bit of a night owl as I don't always sleep well. I've always been an odd bod even before I was diagnosed with MS

So yes, Lisa, you're not on your own and Ron, I'm sure you are doing a fine job supporting Carla. There's some good literature on the MS Trust website and I've always found them helpful - when I was first diagnosed and even now. Keep up the good work!

Lisa: Thanks guys for the responses. I was involved in a chatroom last year and, for me, perhaps selfishly, find it just helpful to know that I'm not on my own dealing with a partner with MS. Obviously you know there are plenty of people out there in a similar situation but to be able to share experiences and listen to others is really helpful, so thanks

Nessie: Well said, Lisa, I agree whole heartedly with you. This is my third chatroom I've logged into and am looking forward to the book about primary progressive MS coming out later in the year.

I don't think you're being selfish, just nosey about something that's happened and what you can do to help. It is good knowing you're not on your own. It's a good way of sharing your experiences and how you've dealt with it, even pinching ideas off others lol

Janey: Hi there! I am 29 and was diagnosed two years ago with relapsing remitting MS but they think I have had it since I was 18. Fatigue is one of the killers for me. I have tried different methods to help fatigue but none so far have been successful. I was wondering if you know of any medication that can help fatigue without putting on weight, as all the ones I have been told about are meant to put on weight, which is not what I want as I want to stay as mobile and active as possible. Many Thanks for all your help

Simon - MS Trust: Which drugs were you told about?

Janey: I was told about modafinil (if that's how you spell it)

Simon - MS Trust: Drugs for fatigue are just part of the approach. As has been said, adapting lifestyle and managing energy levels are also very important

Janey: I know, thanks. I have learnt how to pace myself and also tried to change my whole lifestyle but I am not sure about going onto modafinil and wondered if there were alternatives. Some days I can't get out of bed without a struggle and I am getting married this year and hope to have kids soon after and want to be at my optimum for all of this - if that makes sense

Nikki - MS nurse: Modafinil can be useful for some people and another medication called amantadine also sometimes helps. There is some research and some literature if you or your GP needs this to help you make a decision.

Janey: Thanks. Where do I get the literature and research? I am now at the point that I do need to try something as I was trying to go down the natural remedy route (which is still do for some things) but feel it's not helping fatigue in the slightest. My GP doesn't know anything about MS and nor does he wish to know, so am looking for a new one at the moment

Nikki - MS nurse: Simon, does the MS Trust have fact sheets on amantadine and modafinil?

Simon - MS Trust: The drugs are mentioned in the book *Living with fatigue* and there's also some information about each in the A to Z of MS on our website. If you contact the MS Trust Info Team (infoteam@mstrust.org.uk) we can put together some information about amantadine and modafinil

Janey: Thanks Simon, that's great. I will do that just now

Nikki - MS nurse: Janey, fatigue medication is also mentioned in the NICE MS Guideline 2003

Frank: Don't anticipate that amantadine will make a huge difference. Jennifer was on it for years and I reckon she was significantly more alert when she stopped taking it. Difficult to be objective and the very fact we changed something could have been a motivation. Everyone is different with different responses.

JP: I was diagnosed in 1983. I now have secondary progressive MS and everything is a chore. I work full time and commute (with crutch to get a seat) and exercise about four times a week at home. Walking is both difficult and uncomfortable and after my exercises I need to rest for about 20 minutes before I'm able to function properly. Afterwards I feel better and get the same sort of buzz I used to get when I was able to do sport. I sometimes think I would be better resting more but I worry if I stop it will get worse. I had hip surgery recently after which my mobility got much worse - it was as if the MS took advantage. Does anyone else have the same dilemma?

Michelle - OT: Can I just check, after the 20 minutes rest you are able to function as you usually do (pre-exercise)?

JP: Yes, I'm back to as I was after the rest. Like some of the others have said though, at weekends I allow myself a rest and feel really lazy. Usually spending hours watching sport!

Nikki - MS nurse: It's all down to self-management, so it's not being lazy! Quality of life is the important factor and if that's what it takes... Weekends are for R&R and you don't need to beat yourself up about something you enjoy!

Michelle - OT: If you are back to normal after the 20 minutes then I would say you are pitching your exercise at the right level (if you don't get back to normal after about 20 minutes you are either doing too long or exercising too hard). If you enjoy your rest at weekends that is great - it is what a lot of people do - don't feel guilty! But if your feeling lazy stops your enjoyment, then build in something low level to take away the guilt, then you can truly indulge in your sport the rest of the weekend!

JP: I know you're right, it's just I used to be so active and now simple household chores are exhausting. So much needs to be done but I just can't manage anymore and it's hard

Michelle - OT: It is so hard to adjust to a change in lifestyle. Do you use any other management strategies along with your exercise regime?

JP: From a fatigue point of view, I just avoid going to places that I know will be difficult unless I have to. Shopping online is much easier but it takes a bit of the fun out of it. But another big issue for me is bladder control - when I need to go I NEED to go, and I can't get anywhere fast! So one thing I do is avoid fluid before a trip and massage my bladder even if I don't feel like going so I'm empty. When I'm where I need to be, whether shopping, meal etc, I make sure I know where the loos are and position myself accordingly! Sorry to be graphic but it might be useful to someone!

Frank: Be wary of cutting down on water to avoid bladder issues. We ended up with real problems with bladder infections, shrinkage and strong urine which made things a lot worse. Better I reckon to drink as much as possible early in the day with lots of top ups later and to experiment with the various pants to ensure that when you go out somewhere special, you wear pants that will protect even if you have an accident. Easy for me to say without having MS, not so motivational or good for the self esteem if you are wearing them, but a safer option than drinking less.

Angela: Hi JP. Have you asked to see a continence nurse? I have managed to control my unstoppable urge to go to the loo by taking medication - was a bit of a blip due to fibroid, but more or less under control again now

JP: Yes, I recently got some medications for the bladder. I took one when I was on gabapentin and it left me like a zombie! I'm off the gabapentin now so will give it another go. Thanks,

Angela: I have found all the comments and discussions extremely interesting. I was diagnosed with relapsing remitting MS in September 2006 (I am now 46), but looking back, I'd had it at least three or four years prior to this, it just did not get diagnosed.

I went through fairly classic denial for the first year, until a really bad relapse made me take stock of things. I had a demanding (physically and mentally) full time job and also worked part time in another mentally demanding position, but I continued to live life pretty much as I had before. I think I only really change things when we moved house (to be nearer to my full time work) and this brought on a full blown relapse.

Anyway to cut a long story short, I was finally finished at work last July. I have since found that some of the problems I was experiencing, which had been put down to MS, were in fact nothing to do with MS. I have a fibroid - causing all sorts of problems including bladder, bowel and back pain - also tendonitis associated with my right shoulder bicep. But demyelination of the cervical spine, has left me with a right hand that has permanent numb, pins 'n' needles - any suggestions for this would be greatly appreciated.

Fatigue - tell me about it - it's horrible and nobody understands how it can suddenly hit you - unless they have MS too. I am also now experiencing problems with a completely upside down sleep pattern. I am trying to exercise, have started swimming regularly, doing a bit of gardening - but all to no avail. It is not helping fatigue and is not improving sleep pattern.

Anyway, that's a bit about me. Was relapsing remitting MS but think this may have progressed - but just not going to ask them

Incidentally, it is not easy as I live alone, some partners have been great, others not so. Thanks to everyone, nice to know what you're feeling is not in isolation

Pat: Interesting stuff, Angela, about the sleep patterns. I work full time and find the fatigue management course my local MS team sent me on of great benefit. However, I do find that when I am at my most tired my sleep is very badly disturbed. I know the answer is not to get so tired but that is very difficult if you are still working in an unpredictable job with an unpredictable illness. Is this a known effect of being just over tired?

Michelle - OT: Hi Angela. Sounds like it has been quite a difficult year for you. Unfortunately, strategies that you are putting in place will have little impact on fatigue whilst your sleep pattern is unsettled. The advice for sleep is not unique to MS so just check you are doing the right things - no caffeine after 6, no television etc in the bedroom - there are too many to list but there is lots of advice available. The key thing is not to sleep in the day (for a time until you get your usual routine back). This can be hard when you are not in work. Also try relaxation techniques, as I discussed earlier. Once you have regained a reasonable pattern, then you may find the exercise and other approaches are having some benefit. You also need to think about pacing and planning in amongst these new activities.

Angela: Thanks Michelle, I don't have caffeine at all and drink fruit / herbal teas. My problem is television. It's odd but I can fall asleep to the television. I quite often go downstairs and sometimes in the middle of the night it can be quite relaxing. I don't sleep during the day, but yes, I'm going to try some more relaxation techniques. In fact I have just completed a Breathworks - Mindfulness - Living Well with Chronic Pain, Illness and Stress Course, so must put a few more of these techniques/strategies into practice. If anybody gets the chance to go on such a course I would recommend it

Sue: Every evening around 5-ish my legs seem to give up regardless of whether I have had a busy day or a sitting down day! Is this a common symptom of fatigue?

Pat: The question about the legs giving up at 5 each night seems relevant. I find that my tiredness is not often connected to my level of activity. I can do lots one day and be fine or wake completely wiped out

Claudia: It wasn't until I read the book about fatigue that I realised how complicated it was as a symptom

Simon - MS Trust: The actual level of activity is often unrelated to the level of fatigue, isn't it?

Pat: I agree, and that is what makes it so difficult to manage and what makes all this advice and sharing of so much use, at least you don't feel alone

Claudia: I used to think fatigue was just fatigue, but by tackling waterworks problems and getting a few really quite minor things done at work, the effect of fatigue was so much reduced. I don't think people always realise how many bits go together to add to fatigue

Pat: I find one of the hardest things is trying to explain to colleagues who of course experience 'tiredness' too and feel that they know how you feel. Especially when you have just had a weeks leave from work and are still tired

Claudia: It does seem to be the lack of evidence, doesn't it? How often people have said 'but you look so well...' as I've staggered blearily and leadenly from moment to moment

Michelle - OT: Yes, fatigue can be like a jigsaw with lots of factors coming together. Often, if we don't take time to look at what is contributing to the fatigue, the strategies we put in place are of no benefit and this becomes even more disheartening. So take time out to look at what are the issues that are contributing and therefore what might help?

Pat: Useful advice, Michelle, and although that can help and I have found that putting management strategies in has been really helpful. The 'crashing' tiredness that hits like a brick wall is much harder to cope with, especially when you are working and others are expecting you to do stuff

Michelle - OT: One thing I always suggest to people with MS who are trying to explain fatigue to people without MS is never use the word 'tired'. If you say you are tired, people think they know what you mean as we have all been tired and we can associate with it. Use the word 'fatigue'. It makes people think a bit more. Or use the correct terminology, 'idiopathic lassitude fatigue' - that will make them sit up! No seriously, language is really important. Explain this is fatigue, which is different from being tired. It is like comparing a headache to a migraine. Try and find descriptions they can understand.

Pat: That is really useful. I work in an academic environment and using idiopathic lassitude fatigue will keep them all happy for months. That is a really useful tip, I will try it out tomorrow and see how it goes. You are right just tiny changes like that can make a difference

Angela: You are so right. A previous long-term partner could never get his head round my tiredness. He would always agree and say so was he. Wish I had thought to use the word fatigue, or even better your 'idiopathic lassitude fatigue'. Sounds different.

Nessie: I agree with Pat about colleagues and friends who you work with. You feel guilty because you are tired and don't always want to blame the MS and be tired just like everyone else.

Pat: I agree, Nessie, colleagues eventually get fed up with it. It's OK to be ill for a short time but year after year it just annoys them.

Nessie: Claudia, you are so right, it's what's known as the silent illness. If more people understood it they could help and be more supportive. And when they've done that and listened to you, which is so important, you don't feel quite as isolated.

Angela: Nessie, that is exactly what I found. But it is just so frustrating, when you can't get the time off to pursue problems that you've got, so they just get worse

Claudia: I'm sure there are loads of things that I don't understand or appreciate because I can't 'see' it. Michelle is right about language too. People think because they stayed up until 2am watching the snooker they are sharing in the fatigue

experience. You sometimes think if you went to work with your arm in a cast people would know how to react

Pat: That is so true. When an illness can be seen it is tolerated. I don't think that people don't care, they just forget you are ill and don't really understand since illness is usually a finite thing. I have even had colleagues mention that we will go and carry on working whilst Pat takes her little rest - as if I was attempting to skip work, and that makes you feel dreadful

Jane - MS specialist: Just joining the chatroom and noticed your comments about colleagues understanding fatigue. However much or little you wish to disclose about your MS at work is up to you, but some people have found both the MS Trust and MS Society literature on fatigue, helpful to share with family and friends to help their understanding

Pat: Thanks Jane, I have given these to my line manager. Unfortunately when you work with a diverse set of colleagues in a varied job it becomes very troublesome to manage how much you disclose and I have found it easier to simply be honest and let those I work with regularly that I have MS. However, fatigue is difficult to explain, so I am going to try Michelle's approach of using different words I think

Nessie: My colleagues have always asked how well I've coped and ask how I'm doing. That's OK when you are OK, but it's more meaningful when you know they understand the illness too, if you know what I mean. I'm off work at the moment with depression, which they have related to my MS and how I've coped or battled on the last few years. Now I've hit a brick wall but it is slowly starting to fall down, brick by brick lol. I'm not one for being off and in the 14 years I've worked in a school, I've only had three long periods of time off, this being my third, so I'm not doing too bad I suppose. It's good to know you are not on your own

Frank: I've found ***** or ***** or ***** tired explains things to friends

Claudia: Yes :-) Michelle mentioned idiopathic lassitude whatnot, but there are times when a single syllable of Anglo-Saxon is all I can manage and still seems to sum it all up adequately

Anne: I get a lot of comments of 'you look really well' when I turn up at school. I tell them, well when I am tired I am at home asleep so they don't see you when you are really suffering. I have taken on the attitude that I must look after myself and others' opinions just don't matter as most people try but don't understand. I don't blame them as I found it hard in the beginning to understand this disease.

Pat: Thanks Anne - another great tip. I am a lecturer and so do understand

Anne: I have been diagnosed with demyelinating disease (mild MS), which I finally (I think) sort of understand. I have had symptoms for three years now and fatigue is the worst. I gave up my job as a teaching assistant as it was too much and I had no energy left for my son who is now 10. He finds it hard to understand why I sleep a lot even though I do try and explain.

I was taking amantadine and it did not agree with me at all - it was five months of torture. I slept all the time and had dark moments on this drug. I stopped taking it myself as I didn't feel it was doing me any good. I have felt a lot better since. I know now that the fatigue I have is MS related and not drug related.

I have had no help from anyone except my husband. I have no help with cleaners etc as we cannot afford one, plus I have had no advice or access to MS nurses etc. The only person I have spoken to about my MS is my neurologist.

As I can move around I have not claimed anything. Instead, to earn some money, I have gone back to work to do lunchtime cover at school as that is all I can manage at the moment.

I made the decision that only I can manage this disease that I have and to make the most of my life and watch my son grow up I have had to make big changes to my life. I plan my days in advance and when I have a shopping day, I do nothing else. That way I can manage and rest in between cleaning, washing, ironing, cooking, knitting, sewing, driving my son to activities. I also find that if I drive to work and back I can manage the hour on my feet. I do use my car, funded by myself, a lot and would not be able to do all I can without it.

Simon - MS Trust: When you say you've not seen an MS nurse, is this a choice or do you not know if there is one in your area?

Anne: I don't have any details about MS nurses and have never been given any. I did ask for a referral but it has never happened. Don't know if I am classed as needing one or classed as not needing one. Thought my neurologist was going to refer me but it never happened. So I have just managed on my own and researched this disease and got copies of my hospital notes and MRI scans etc to help me understand it

Denise, MS clinical specialist: Anne, it would be good for you to see an MS nurse. Do you have one in your area? Your neurologist could refer you to one or the MS Trust could tell who covers you. Were you prescribed amantadine for the sleepiness? Modafinil is another drug that can also help this

Simon - MS Trust: We have a map of MS nurses around the UK. Some you can contact directly, others you need to get referred to. If the info isn't clear from the map, contact the MS Trust Info Team and we'll see if we can point you in the right direction. There are still gaps in some places, but there are now more than 200 nurses across the country

Anne Thanks for that. I would find it useful to see an MS nurse. Actually I think I would have found it useful a long time ago. Just to have someone there you can contact when things are going wrong and who understands would be helpful. I will look into this again. Really interesting

Caroline: I was diagnosed with MS September 2004. I was given carbamazepine immediately. My medication has never been reviewed. I know my MS has gotten worse. We have moved area and I am due to see a MS nurse on 10 May. So for three years I have had no contact with anyone about it. Basically, I deal with it. I pace my life - do a bit and stop. The worst thing for me is fatigue. I was told to think of my body as a battery that runs out of charge and to stop and rest means this can happen. What can I expect of the MS nurses when I see them for the first time in a new area?

Jane - MS specialist: You could ask your GP or MS specialist (if you have one / when you see one!) for a referral to occupational therapy (OT) for Fatigue management - either an individual or group program.

Caroline: Thank you. I am sure I will get the correct guidance. I have tried to carry on as best I can and also being in a new area I am a bit nervous of driving here, especially in the afternoon.

Simon - MS Trust: As part of MS Awareness week we have posted an interview with a nurse, talking about the sorts of thing her job involves

Caroline: I have always said that from the minute of diagnosis I have been left on my own to deal with this. I too have had to struggle at times to get the correct information. I have always felt that when you get diagnosed you should be given an information pack on who to contact, where they are and your rights at work. It was all such a battle for me. When you are fatigued it is the last thing you need to be doing.

Nessie: Anne, sorry to hear you gave up your job as a TA in a school. That's what my job is and I've been lucky that I've had a supportive head in the past. I have a new head now and went off work as a result of a bad day. It's left with me feeling a failure. I was always worried about being able to do my job and if I couldn't would my illness be to blame. Yes I've had times when I felt I couldn't carry on but...

My best friend always says to me you are not ill, you are not disabled, but are someone with a disability. Get in touch with your human resources (HR) department because there are people out there who can help in your workplace. Remember you come under the disability discrimination act.

Don't give up what you enjoy doing - just do it in the middle lane instead of the fast lane.

Anne: Thanks for that. I gave up my TA job myself. The school wanted me to stay but I put myself and my family first and I am glad I did. They were really pleased when I went back at lunchtimes - I can manage that at the moment. I have definitely gone to the middle and sometimes to the slow lane but it is not so bad to take things at your own pace is it.

Nessie: I'm glad you are enjoying what you are doing. I've cut down on what I do at school and in an after school club. They have been supportive, but unfortunately as I've gone off this time, the new head had only been with us for four weeks. Hopefully all will be well when I go back, but it's hard when you've had a knock and aren't sure how you will be when you go back. Work does keep you going and, like you, I feel like I'm in the slow lane and may have hit the hard shoulder. The MS Trust are an invaluable site for gaining info and they have

helped me learn about my MS. Those at school who wanted to know have also found it interesting. You'll get there and you certainly seem to be getting on the right track.

Caroline: I don't work any more but I did. I was the first person working for a large group who had been diagnosed with a disability. They didn't know what to do with me, how to help me. Every thing I found out I told my manager. I would get letters from him sounding very nice and sympathetic, but it was just covering the company. He asked me if he was recruiting for a job and someone came to him and said they had MS did I think he would employ them? I said if they could do the job well then I would like to think the answer would be yes. He said, "No, he wouldn't". This was what I was up against. They wanted me out and succeeded

Jane - MS specialist: Fatigue can be one of the main reasons why people with MS give up work. I would encourage anyone who is in this position to seek the support of your MS nurse/ specialist and/or occupational therapist to ensure you get the right support with this big decision

Simon - MS Trust: Our book *At work with MS* may be some help. If nothing else it shows how the attitudes Caroline has had to face are now in direct contravention of the Disability Discrimination Act

Jane - MS specialist: Yes, definitely. People have also found the Disability Law Service a fantastic resource

Nessie: I'm sorry that Caroline had to go through that - it is hard to deal with a disability if you think it will stop you from doing your job. Up to now I've been lucky but how long will that luck last? I'm not a person that likes to sit still so that's my battle at the moment. Although I'm getting better, it's so much easier when people around you understand your MS and the affect it has on you. Unfortunately that only comes with time

Denise, MS clinical specialist: Caroline, that is a story I've heard before. Fatigue is high on this list for reasons people give up work. It's a shame you didn't have any support to continue with the job. Often a nudge from a health professional can help. Employers should make reasonable adjustment under disability law

Caroline: Yes, I know. But I worked in a call centre and was very good at my job. Two of the women I worked with where overheard telling my manager that I was 'milking my illness' and he let them get away with it. I worked for a car dealership and had to work evenings and found out that I didn't have to work late hours. The women I worked with resented it. I was allowed to park on site because of my fatigue, again they resented it. It was a nightmare with no support

Jane - MS specialist: This sounds like an added stress you could do with out. Do look at the books we've mentioned and try to get support from your MS specialist nurse or an OT. Some of the written info could help you with communicating about your MS.

Caroline: Thanks Jane. It's three years down the line and I still feel I was treated appallingly. I am seeing the MS nurse in a couple of weeks here. Sorry about my moaning. Thanks for listening

Denise, MS clinical specialist: That must have been a difficult position for you to be in. When colleagues behave like that you dread going to work. It's hard to

make people understand and sometime you don't even want people knowing either. Because fatigue is 'hidden' it's even harder and it's so not like 'normal' fatigue others find it extremely difficult to get their head around

Caroline: I can't begin to explain what a difficult time in my life it was for me. I cannot believe people could be so horrid. I did dread going to work. I was snubbed, ignored, excluded... you name it, it happened. My manager said, just before I left, that he found me aggressive. What he saw as aggression I saw as frustration. He knew what was going on. I was totally upfront about my MS. The day before I got my diagnosis said to my manager, "I don't know what's wrong with me but I feel as though I am in a dark tunnel trying to drag myself along." He handed out leaflets about MS and one girl actually made a point of throwing it in her bin as I walked in the office.

Jane - MS specialist: I'm sorry to hear about this. To anyone else in this situation, please seek support from Occupational Health at work and your Human Resources department. Also your MS nurse and/or specialist occupational therapist

Nessie: Hi Caroline, sorry to hear what you went through. As my doctor said to me recently, there comes a time when people around you need educating about your disability, but those that matter and want to know and care will be interested

Although I'm not working at the moment, all the people I've got around me (MS nurses, doctors, counselling team, family, human resources and occupational health) all agree that I'm fit to work but just need to take a break and get the help I need to help me deal with how I am. It's hard work when you're used to being a very active person to go to having no confidence, but there is help out there you just have to ask and don't give up asking. That's how I got to where I am - just having a rest at the moment and learning not to be hard on myself.

Denise, MS clinical specialist: Nessie, it's sounds as though you have a really positive attitude. Taking time out is sometimes what's needed. Well done

Nessie: Don't give up. I hope you get a new job with people who will understand you and help you. Do read the books mentioned previously as they are very useful. Because it took along time for me to get diagnosed, all my friends and colleagues sort of grew with me. My new head, I suppose, wants the best for me and the well being of those around me, so its learning curve for us all

Caroline: Thanks Nessie. I don't want to give up. It sounds stupid but I want my life back how it used to be, I know that will never happen and my husband says he wants me back as I was, bright and bubbly and the life and soul of the party

Nessie: Don't give up. Remember you are the same person, just living life a little differently. I always say MS has to put up with me. There will be good times ahead for you Caroline, keep going. Although neither of us are the same person, we just live life differently and can still have a laugh. Those around you that support you will want to understand and help, and will do

Caroline: I don't think the people around me do totally understand. They still see me as me. The only one that totally understands me is my sister. She only has to look at me and says "Are you tired?" My husband admits he doesn't always understand it, although he's getting better. My dad, who is nearly 80, just treats me as he's always treated me. I guess that's fine but I don't want to remind him.

My mum was diagnosed with cancer a month after I was diagnosed and we lost her nine months later. It's been a lot for my dad to take in.

Denise, MS clinical specialist: One thing I experience time and time again is people with great resolve and determination... or stubbornness as you say! It's hard changing a life time of habits and a real challenge to not give in. Sometimes though, a small change enable you to do the things you want and you find your not wasting energy on things you don't need to do. For example, one person started using a scooter to walk the kids to school. It was a huge change for her but it gave her so much back and she was able to do what was an important role for her

Jane - MS specialist: Going back to the earlier comments on how to explain MS fatigue, I've heard many people say 'fatigue' just doesn't explain it. Some have benefitted from the support a group can offer and discussed how to talk about and explain fatigue to family and friends

Denise, MS clinical specialist: I agree. When I've run fatigue management groups it the discussing with others that people the most beneficial. Some MS Society branches have local support meetings

Ron: If this service could become available one day a week it would be great not only for people such as myself but for the people that do have MS. I only mention it as I am very pleased with how this has been done and how it has done so well.

Simon - MS Trust: Maybe you could try our Facebook group. This has a discussion board part and people do use it to seek opinions and ideas

Ron: OK, I'll take a look at that

Sara: I was diagnosed 8 years ago, with relapsing remitting MS. Things I do:

- 1/ On Tysabri
- 2/ Proactive rest each day
- 3/ Work from home
- 4/ Delegate washing, ironing, cleaning and some cooking
- 5/ Swim
- 6/ Enjoy reading with my kids

Since I have been on Tysabri I have felt able to deal with many things when previously I was too tired it has been great

Denise, MS clinical specialist: Glad to hear that things are easier for you now. Proactive rest is a great way of managing fatigue. Balancing rest and activity is tricky if you have a family and home to run. You've obviously hit a good balance. What tips can you share?

Sara: Take control of your treatment - I asked for Tysabri
Treat symptoms - I have seen a continence nurse and physio
Exercise - whatever you can do
Accept some things, fight other - prioritise important stuff that you can influence

Fatigue is frustrating and not obvious to those around you. My husband and I came up with a phrase 'struggling to cope' which I could use to communicate with him so that he could help or organise help for me. Seeing an OT when I was originally diagnosed with chronic fatigue was life changing as it gave me control back of my time.

Nigel A: I've had relapsing remitting MS for three years and it was late to happen as I'm 54 this year. I work full time in an office environment, and some days I now get worn out literally just thinking. I'm learning how to manage the fatigue, mainly by trial and error, and it's the most obvious symptom I have at this time. (Apart from a real aversion to uneven surfaces, which tire me out unreasonably fast!)

I've learnt to sit at every opportunity as standing up will wear me out quite quickly without realising I'm doing it. If I walk for any distance I will use a walking stick, and I think this mainly helps because it makes me walk slowly, so I can go further. I'm always worst in the mornings, and supermarkets are definitely to be avoided, even leaning on the trolley doesn't help much. Luckily I look so pasty when I'm worn out my wife knows this isn't just a new found aversion to shopping!

When I want to do something at home I find that it's best to be able to just stop when I get tired. So things like gardening and DIY outside are good. Indoor jobs are bad, as you often can't just walk away from it when you wear out. I rest as I get tired, and then carry on, with each period of work getting shorter until I either finish it, or just have to sit for hours to recover. I don't get sleepy, but I certainly do have to rest. (I sleep normally at night.) Stamina does not increase with frequency, and if I wear myself out too thoroughly it will persist the next day. Luckily I have a sitting down paid job!

The only 'medicine' I take is Rebif, but I did quite a bit of reading and also supplement with linoleic acid, omega 3, and vitamin D, and I've cut back quite a bit on red meat and saturated fats. A friend has ME and he recommended a mixture of 3 amino acids - I glutamine, I ornithine and alpha ketoglutarate - which removes his symptoms so long as he takes it. I tried them and was initially pretty dubious as it seemed improbable to work, but was pleasantly surprised when it made a detectable improvement. My consultant sees no harm in it as they are well known supplements.

I agree wholeheartedly with those comments about how you look to others. Many people just can't grasp there's something wrong and that you feel like rubbish as you look OK to them

Mickey: Yes, short breaks are key. I will be absolutely shattered one minute and then take an hour nap and recover but the naps screw up my sleep cycle

Jane - MS specialist: It sounds like you are practising many of the tips we encourage people to use for fatigue management;

- Sitting where possible
- Knowing what time of day you are at your best
- stopping before you get tired
- ... any other handy hints you would like to share?!

Denise, MS clinical specialist: It sounds as though you're doing a good job of pacing and resting. It's hard to get it right and often, like you, people find if they

overdo it one day they pay the next. Sometimes breaking down tasks into even smaller chunks is useful as is enlisting help or delegating if you have someone who help - especially if you want some energy to do something specific later in the day. Fatigued thinking is a common difficulty. It helps to pace this too and rest between very mentally demanding tasks and to try and do those activities when you know you won't be distracted. Have the amino acids helped the fatigue?

Nigel A: I don't actually stop before I get tired as I never know how long I will go. I think it's resting as soon as you realise you've got fatigued that helps. Doing a bit more once I've got that far makes it much worse for me, which is why I tend to avoid things which really must be finished on the day you start them.

There's a psychological element in it. If I feel I have to do a job, it's much harder to do than something which I actually want to do. It took me quite a while to figure it out, and I was depressed for over a year and did very little apart from going to work as I didn't want to feel poorly from doing a simple chore. I finally thought stuff it, I'll only do those things I want to do round the house. Hence the bathroom floor is never going to be laminated - at least not by me! But I will make a paved area in the sunniest bit of the garden this year, even if it takes months.

Thinking of a list of jobs which could be done made me not want to do anything. So forget the list and do things which you want to do, and get someone else to do those things which need to be done but you really don't want to, if you can!

I also think it's important to have a hobby or other involving interest. If I sit and do nothing much, I will soon start to think about being tired and those aches and pains. If I'm thinking about something else I usually forget how I'm physically feeling. At work I might feel off colour quite often, but getting involved in the work usually makes me forget it - until I stand up.

It also took me a long time to realise that the slightest uneven ground wore me out very quickly. Where we walk our dog looks flat, but it's a river bank and has a 1 or 2 degree slope to the side. It's only obvious in mid-winter when the grass is shortest, and it took me two years to see why I got so easily tired on such a short walk there, when I can go a fair distance elsewhere. Cobbles are a complete no go area. I've also noticed that the pavements around work are quite angled which is why I walk poorly in the morning. It's usually much better in the afternoons, and I now try to do any physical tasks after lunch.

I see some talk of work problems. I think people just don't think you're ill as there's nothing they can see unless an obvious bit stops working. It's very hard to convey what's actually wrong with you when it's MS. As someone said earlier, everyone thinks they know what 'tired' feels like but that's just not fatigue!

Caroline: The invisible illness

Denise, MS clinical specialist: It's interesting you mention depression. It's something we British don't like to talk about. Sometimes when people explain their fatigue to me they say that they are 'tired all the time'. This will trigger me to dig a bit more about how they are feeling and how their mood is as it's a classic pin pointer for depression, especially if it's coupled with early morning waking. Fatigue in MS is complex and has lots of components to it. If someone is depressed treating that treats the fatigue. It's important to understand what's causing the fatigue and what type of MS fatigue someone has to be able to offer the right advice

Jill: It is true that fatigue (or lassitude) is a side effect of depression and that depression (or feeling down) is a side effect of fatigue. When I had a dreadful bout of depression a few years ago I could hardly get out of my chair

Jane - MS specialist: That's a good point and some people may need help with breaking that pattern/vicious circle

Jackie: I have relapsing remitting MS, diagnosed five years ago at the age of 35. I am on Rebif injections. I have a son with autism who needs a lot of care and has poor sleep (most nights he is awake at 3am for a few hours or does not go back to sleep at all). Hence I have poor sleep! I also work part time two evenings per week, not finishing until 10.30. In the school holidays I am finding it very difficult as I am unable to rest during the day whilst caring for my son and then have to go to work. This week I have felt such incredible fatigue to the point of not having the strength to cut a piece of bread!

It may sound obvious but will lack of sleep and stress cause my MS symptoms to exacerbate, as this seems to be the case? After a bad night my arms and legs feel weak, I have numbness and muscle stiffness. This week I have had to take sickness absence from work as I have felt so bad. I am going to ask my employer for a term time contract so that in the school holidays I won't have to work and will be able to go to bed earlier and manage my rest better. I know they will not give me this type of contract easily but I feel I have a strong case and will only have absence from work with illness if I carry on like this.

Are there any medications to help with fatigue and what are the side effects? Any advice is greatly appreciated

Caroline: When I was working, one of the things I was told was that they company had to accommodate me. Which was when I got evening shifts knocked on the head

Denise, MS clinical specialist: Yes, Jackie, lack of sleep and stress will an effect on your general wellbeing and certainly fatigue. Asking for support from your employer is a really sensible thing to do and a term time contract would definitely help. Have you thought about seeking advice from your local Disability Employment Advisor? They are based in Job Centres and can work with you and your employer to get the balance and support right. Do you have any support in caring for son? You could have a carer's assessment by a social worker and they may be able to you with benefits, respite, domestic help etc

Caroline: The Disability Employment Advisor helped me with the information about accommodating me at work. They were in the phone book and I rang them from my bed one day.

Carole: I have been prescribed amitriptyline at 10 mg dose and wondered if this is a standard or low dose prescribed initially to patients

Denise, MS clinical specialist: Amitriptyline is usually prescribed in this low dose initially. It's dependant on what it's aiming to treat

Edward: Previously we were talking about Chinese supplements. I've been wary about taking western anti-MS drugs as they appear to destroy some parts of the body rather than the Chinese supplements which aim at stimulating the body to produce compounds such as interleukins which regulate the immune system. Of course, some of the mushrooms are dangerous for MS sufferers as the lymphocytes which are stimulated are the ones which destroy myelin although are prescribed in Japan as anti-cancer metastasis remedies. I think it is a pity that our research scientists don't work with colleagues in Japan as they do with American scientists. Japanese researchers have published many papers on neurological investigations including MS.

When I left this site earlier, it was for what the MS Trust calls a 'power nap' in its fatigue publication. It works in restoring concentration and the ability to carry on for a while but it needs to be in a quiet room away from distractions

Denise, MS clinical specialist: Power naps are great restorers. That's a great tip. Be careful that they are not for too long or too late in the day as they can interfere with night time sleep and knock our 'internal clock' completely out of kilter!

Jane - MS specialist: It's important to check with your MS specialist that your alternative medicines or Chinese medicines are compatible with your prescribed medications. If you don't have an MS specialist, check out your Chinese medicines with MS Trust information team and see if they have any information on them.

Edward: I don't take any prescribed medicines for the reason that I mentioned before. I will look up amantadine, which has been mentioned earlier today several times to see what it does apart from destroying viruses, but I'm frightened of all the others that I know about. As long as I can just keep sort of going, I'm OK

I've talked to the MS nurse about all the Chinese medications that I know about and given her copies of any research that I have found. She didn't know any more than me. My GP says that he doesn't have time to look into anything that NICE hasn't advised, and I don't really want to disturb the neurologist as he is very busy

Simon - MS Trust: There are a couple of books by an American doctor called Allan Bowling that look at alternative approaches to MS. He tries to be non judgemental and to assess what information is available - neither blindly advocating nor dismissing out of hand. You can find his books listed at the bottom of this transcript. He used to be linked to a place called the Rocky Mountain MS Center and their site has a good deal of information about a range of approaches

Edward: Thank you. I'll have a look at this when today is over

Simon - MS Trust: Otherwise it seems a sensible approach, having checked to make sure there are no obvious problems, interactions or known side effects, to try things one at a time so you can tell which one is working. Also wise to ignore any hype (for or against) and monitor how something works for you. If it works, great, keep going. If it doesn't, well, remember that not everything works for everyone and try something else

Edward: That is what I have been doing. I started after my hand tremor was erroneously diagnosed as focal dystonia and the Dystonia Society suggested acupuncture, which is only available on the NHS for pain. I went to a Chinese practitioner who prescribed lots of things and then started to try some. Some

work, some don't. I agree that one at a time is best starting with a lower dose than stated and see what happens! I have some conclusions but I hesitate to list them because they might not work for everyone. I am not a doctor or a Chinese practitioner. That's why I asked for other people's experiences today

Denise, MS clinical specialist: Someone earlier mentioned that they get tired even standing. This is specific muscle fatigue or sometimes known as nerve impulse fatigue. It is usually helped by a short, physical rest. Does anyone experience this?

Carla: I get that. Queuing to pay in a shop can be worse than doing the shopping

Jill: Friends have told me that yoga and pilates can help with fatigue. Is that right? Has anyone else tried this?

Mickey: I have definitely found yoga and pilates to be very helpful.

Jill: How have yoga and pilates helped? Is it the relaxation, or the postural stuff?

Jane - MS specialist: I know people who have found pilates or yoga or meditation helpful. Gentle aerobic exercise is good for fatigue and keeping those muscles in condition.

Simon - MS Trust: The May 2010 issue of Open Door has an article on yoga.

Jill: Thanks Simon, I'll look out for that

John: I suffer with fatigue like most MS sufferers but I have found a solution for me that might help others. I purchased for the princely sum of £1 the exercise DVD for people with MS. Mr Motivator features and he is very good. I find that if I get up feeling fatigued, I do the warm up exercises, which is standing, and then some of the individual sections depending on how I feel. The exercise, some of it sitting, seems to get the blood flowing and the muscles warmed up and afterwards I feel a lot better. I have even been known to get up fatigued, do exercise and the go shopping with my wife! Try it, you have nothing to lose!

Simon - MS Trust: John, thanks for that and I'm glad you found it helpful. The DVD is called *Move it for MS*. If you follow that link you can watch the warm up section on the MS Trust website. There is also a whole section of the website with exercises for people with MS. You can find this through the Publications pages

Denise, MS clinical specialist: Exercise can definitely help with deconditioned muscles, which we get when we limit activity due to fatigue! It can become a cycle. We limit activity to avoid fatigue but that causes deconditioning of muscle, which hinders our muscles efficiency and so impacts on fatigue!

Aerobic activity has been shown to improve fatigue. Again balance and pacing is key. Learn your limits and don't over do it and pay later. Schedule exercise in to your routine just like any other activity. It's easier to keep the commitment then

and make sure its fun too. Yoga and pilates also help breathing, core stability and posture which are import to keep fit. Exercise also helps improve our mood which may be low at times too

Jane - MS specialist: Good to hear Mr Motivator has been successful ... I've been plugging it!

Tim: It probably sounds a bit weird - certainly counterintuitive - but I find that going out for a run helps me shake off the worst of my fatigue. I'm still tired at the end, but it's an honest sort of a tired that I can explain. Helps me, anyway. As Denise says, it also helps my mood too. Love those endorphins!

Jane - MS specialist: That's good to hear, but it's important to choose an exercise that you are going to enjoy! Swimming can be a good one as impact of gravity is reduced. But check the water is not too warm as this will impact fatigue. With all exercise it's important not to over heat as this could make the fatigue worse

Tim: The worst for me is when I suddenly run out of energy. Sometimes for no apparent reason at all. Have you ever read Christine Miserandino's Spoon Theory? It's about Lupus, but it seems to apply to MS too, when you suddenly run out of spoons. I just go into shutdown and pretty much have to go to bed. I'm not sure if there's anything you can do about it either, other than be conscious of how many 'spoons' you've been using

Denise, MS clinical specialist: Spoons Tim? I'll have a read. In MS we sometime talk about battery power. What you're describing is a specific type of MS fatigue known as idiopathic lassitude. I tell people that translates as 'I'm knackered and can't move an inch'! Basically it's an overwhelming sense fatigue that comes on suddenly without warning and often without activity and sometimes even when resting. It's very difficult to combat and people describe it as hitting a brick wall. It often occurs in the afternoon around 3 o'clock. This seems to coincide with our natural body clock, which wants to shut down at that time and send you to sleep. Ensuring you eat a snack mid afternoon is good as blood sugar dips then too after lunch. A power nap may help too.

Any one else got any tips?

Tim: It does often strike mid-afternoon (either that or when I wake up, especially after injecting Avonex, when I sometimes feel like I've been hit by a bus). A mid-afternoon snack helps? That's brilliant news and just the excuse I was looking for!

Frank: Whilst this sounds good, my wife Jennifer is so easily tired that I doubt there is much value from the exercise she is able to do before running out of steam. I'd reckoned that she could gain from undertaking stimulated exercise and we used a vibrating plate machine. The bulk of the work is done by the machine whilst Jennifer gains some muscle tone. This is pretty limited in its aerobic content but I feel the muscles still get a work out. Any thoughts or alternatives for those with limited energy or control?

Denise, MS clinical specialist: Thank you, Frank. I agree that exercise is not always possible. If someone is able to get in a swimming pool as Jane suggested that's a great way to get some exercise. Even floating is good. Some areas have swimming sessions for people with disabilities and even have hoist to help them get in. Your local council would know. Maybe your wife would benefit from seeing a physiotherapist who could advise further and help work out suitable activity

Jane - MS specialist: It may also be worth checking out *Move it for MS* (Mr Motivator DVD) for some chair based exercises which your wife may enjoy... it will certainly make her smile!

Caroline: I've been invited to four weddings this year - one being this Saturday. Any tips for surviving the day without having a bed?

Denise, MS clinical specialist: Try to bank some energy prior to the day. Basically try to limit activities and rest as much as you can the day before. If you can, during the day sneak off for a short quiet rest somewhere or even a power nap if needed. Make sure you eat regularly too to keep you going. So often people skip meals. It's basic advice but people do find these tips help.

Caroline: I am trying to have a quiet week but still need bits for the wedding so I am trying to pace myself. I will eat regularly - I don't have a problem with that. Thanks for the advice

Jan: I am always tired, I yawn continuously, I can't keep my eyes open while watching TV, on the computer or my DS game! Is there anything I can do to help myself? I get at least eight or nine hours sleep a night, I don't work, but I am still tired!

Carla: I've missed the end of most Grand Prix so far this season. My brain goes AWOL and I can't concentrate. Sleep seems the only option

Bill: It is like a jigsaw, isn't it? So many bits go together, and the bits that work for some people's puzzles don't fit in yours

Jane - MS specialist: It can be a challenge working out what's going on. For some people, keeping a fatigue diary for a week can help identify any patterns. There is an example of this in the MS Society's book on fatigue. Your MS nurse or an OT could help you with this

Magsy: I suffer from fatigue even though I go to bed at 9 o'clock each night. I try to rest in the day but this doesn't seem to work. I have taken Symmetrel (I think it's called) but found this not to work so have given up taking this. Is there anything else I could take or try? It's a real bug bear!

Denise, MS clinical specialist: Are you describing sleepiness?

Jane - MS specialist: Symmetrel or amantadine can be used for fatigue in MS. It's more commonly used for Parkinson's disease, so GPs may be surprised or reluctant to use it in MS. You can refer them to NICE guidelines. Another medication people have used is modafinil (Provigil). Your neurologist or MS nurse could discuss these with you and ask your GP

Denise, MS clinical specialist: Both amantadine and modafinil are only usually effective if you have excessive sleepiness. They don't generally help lassitude or muscle fatigue. It's probably worth discussing this in more detail with your

consultant, MS nurse or OT. It may be that a bit of unpicking of your specific MS fatigue symptoms is needed to identify the best treatment.

Liz: Is there any advice on breathing problems? My respiratory muscles are quite badly affected now, and the effort of breathing leaves me with very little strength and energy, plus a frequent feeling that I'm going to suffocate or faint. I feel that I would have a lot more stamina if I could breathe properly

Jane - MS specialist: You may wish to seek your physiotherapist's advice on this and, if needs be, ask her about seeing a respiratory care physiotherapist. It's always good to check with your doctor or GP that you don't have any underlying chest problems or health problems that may affect your breathing and that you are not brewing a cold or chest infection

Liz: Thanks - I'll ask my MS nurse about this

Denise, MS clinical specialist: Some people experience a feeling of tightness around their torso or a squeezing or tight hug. Is this what you are describing?

Daisy: How can I exercise without being utterly wasted at the end of it?

I appreciate there are an awful lot of variables and one answer can't work across the board but I hope, as MS professionals you've noticed 'trends' that may shed light on a couple of points...

My left side is getting very gradually weaker (left leg in particular) so I can't walk as far as I used to even with the stick I've been using for the past year. I've been using an exercise bike at home for the past two or three years (I live in Cambridge and used to cycle everywhere - static bikes made no sense at all). I've turned the resistance down, take regular breaks and try to not 'push it' but occasionally I can still feel as if I've run a marathon - weakened legs, limping even more than usual with vertigo/balance issues for a few hours afterwards.

I was diagnosed in '93 and have been lucky enough to be able to choose not to be on any CRABs [disease modifying drugs - Copaxone, Rebif, Avonex, Betaferon]

I haven't had a new attack for a few years - just a gradual worsening of previous areas of damage. Am I right in thinking interferons aren't going to be of use anymore?

I believe exercise has done me an awful lot of good (hated all things sport at school so this has surprised me more than anyone) but am I doing more harm than good?

If you look at the facts, my walking has been getting worse and the taking up of regular cardiovascular exercise hasn't improved matters (since none of us have a control I don't strictly know whether it has slowed the progression or speeded it) but I get the feeling exercise is a 'good' thing. Is this right or am I swallowing a received wisdom without looking at evidence? Is there a way I can be more scientific with my efforts at pacing rather than just going by how I feel?

Might there be warning signs before being 'wiped' is reached that I've not noticed?

I mainly work from home and don't go out often so I try to get a number of things done if/when I do go out - balancing this with pacing the day's activities I'm finding a challenge.

Any thoughts?

Jane - MS specialist: I'm sure your persevering with exercise has been an investment and no doubt Simon can highlight information from MS Trust on benefits of exercise. Try and find something you still enjoy do little and often. If possible stop before you get tired and try and time table in your other priorities - that means some fun things as well as the must do's and chores!

Simon - MS Trust: There is information about some of the research into the value of exercise for people with MS in the Staying Active pages on the MS Trust website, which also contain a range of activity ideas from team sports to more gentle leisure pursuits

As for the beta interferon drugs (and glatiramer acetate), these are thought to work by reducing the number of relapses someone experiences. As a result, they are not used with people with progressive MS who don't have relapses. There is more information in our book *Disease modifying drug therapies*

Kathy: I am 61 years of age and have been diagnosed with secondary progressive MS since March 1997 and have been not too bad up until last year when I had my worst fall. Since then I have developed osteoarthritis in my left hip - my good leg. I have had a dropped foot in the right leg and used a splint for 12 years and my right hand has gradually become useless over the years. I am now using a power chair but try to walk when I can with my rollator... slowly but surely.

Now to my main question on fatigue. I do get quite fatigued especially when I have been slowly walking, which uses a lot of my energy. When fatigued I get quite frightened as I feel on my last legs so to speak and feel I'm not long for this world. Is this a normal reaction? I am sure most people would probably feel the same but would appreciate some comments from the chatroom. I am usually very positive when I feel good inside but hate feeling fatigued. I hope you can understand what I'm trying to say

Jane - MS specialist: I wonder if it would help you to see a physiotherapist and occupational therapist to talk about your fatigue, the impact on walking and the fear of falling or your legs giving way. The physio may be able to help you incorporate standing and stretches into your daily routine and if you needed to use your powered chair this could make mobility a little less stressful

Frank: My wife's reaction to her fatigue is as you've described... usually accompanied by "I hate this life" and "I don't want to die". Seems like the only sane reaction. Fluoxetine (Prozac) does make a difference. It was really noticeable when a GP suggested slowly reducing the daily dose (now reversed)

Edward: Would FES (functional electrical stimulation) or EMS (electro-muscular stimulation) help with fatigue?

Jane - MS specialist: It would be worth discussing this with a physiotherapist. In principle, any mobility aid that helps you walk more evenly, or correctly (so to speak), and thereby use your muscles more efficiently, should help with fatigue. Don't wish to be a bore but there's a factsheet on this too!

Simon - MS Trust: The research into FES in MS (some of which the MS Trust has funded) found that it helped people walk further and faster than without the machine. Presumably this is because they are using less energy when walking, so it could conceivably help to some degree with fatigue. As Jane says, there is a factsheet on FES too

Denise, MS clinical specialist: FES generally helps with muscle weakness and is specifically used with 'dropped foot' when someone can't actively lift their ankle up. I'm not sure it would help with muscle fatigue. A physiotherapist who is experienced in prescribing FES could assess this for you best.

Edward: I did see a factsheet on FES, which I shall re-read, but I don't remember it mentioning MES which is like electro-reflexology and is supposed to stimulate acupuncture points in the sole and heel of the foot. I also don't remember whether or not the sheet mentioned fatigue

Simon - MS Trust: The MS Trust sheet doesn't mention MES

Karaline: A while back in this chat there was some talk about the connection between fatigue and depression. I suffered on-off depression every couple of years for decades before my MS was diagnosed. Though I resisted drugs for treatment of the depression for ages, when I was at last encouraged to try Prozac (fluoxetine) I felt a huge effect. I remember saying over and over to people 'it gives my brain energy - enough to fight the negativity!' As fatigue is my most debilitating and obvious MS symptom now, I suspect it was the cause of depression all those years ago. Does that sound likely? I am currently trying rather huge doses of Prozac on my neurologists advice. Has anyone else found this SSRI helpful?

Denise, MS clinical specialist: That's possible. Sometimes the area and process of the MS inflammation itself in the brain actually causes depression as a primary/direct symptom. Sometimes depression is a 'reactive symptom' to the MS and coping with the condition etc. Depression itself as a condition causes fatigue. Does that make sense?

Karaline: I suppose it doesn't matter what the cause was years ago, really. I've just got to find the best way to handle fatigue now. I really believe that depression is a logical consequence of being stupidly immobilized if you are a person that aims high and doesn't forgive yourself easily (as I was).

Jane - MS specialist: It can be a challenge to have to shift and refocus those goals, particularly if you have been a driven achiever!

Denise, MS clinical specialist: You know, so many of us think we're superhuman and can and have to do everything ourselves. You may be able to be referred to an occupational therapist who can help with a fatigue management programme. Sometimes these are run as groups

Karaline: Not sure I ever achieved very much, but I was driven :-)

Kate: I think being fed up is a normal reaction to some of the MS symptoms and should not be turned into clinical depression. I wonder why habituation is not mentioned in relation to MS. This explains why I get tired and need to rest and then can do things again. If the nerves are damaged the extra effort of getting the messages through perhaps habituates the nerves.

Denise, MS clinical specialist: I agree with your comments. Fatigue in MS is very complex and it's tricky to unpick all the components. Your description of habituation is a great way to describe what happens in muscle/nerve impulse fatigue and also mental/cognitive fatigue. People fatigue after activity, rest and recover and can then go again. There is thought that the extra effort needed to send a message (the nerve impulse) to say a muscle to tell it to contract for example, causes a flooding of chemical at the exchange junction and this stops the message getting to it's destination. These chemicals are present to make the message 'jump' into the muscle normally, but too much is produced because the message is weak. During rest these chemicals are reabsorbed and the nerves can fire off the messages again. Does this make sense?

Karaline: I think fatigue can be explained by something one of the lecturer's at the MS Society conference described some years back. He was talking about the brain's ability to repair the nerve damage and how in experiments they watched the electrical brain activity of MS sufferers trying to do something they found hard, eg if someone had difficulties moving a finger they would get them to try to move the finger repeatedly and watch. Where a person with no nerve damage would achieve the movement and just show clear brain activity along a few paths, the MS affected person would show crazy amounts of activity shooting off all over the place. It's as if the brain doesn't give up, and tries to find a new route through the damaged pathways. Keeping on trying to do a movement SOMETIMES lead to an improvement in the ability to move, and a settling down of brain activity, but often there is never any improvement. To me this explains why doing something like trying to walk if you have a damaged sense of balance, or trying to think when your brain is in a fug, just exhausts the energy out of the brain.

Suzanne: Isn't there something about a repeated action sometimes causing the nerves to short circuit so something you start of doing OK becomes tiring and hard work (even if it isn't of itself a tiring activity)

Denise, MS clinical specialist: Yes that's right. It's part of the same process but a different wording. It's complicated isn't it?

Kate: Karaline, have you heard about neuroplasticity? There has been some research done with people who have had strokes and they are 'forced' to do things with the limb that's affected and the brain fires up in new areas. I've also read bits about neuroplasticity and MS. I have a book about the research done in the last ten years or so but have lent it to someone and can't remember the title, but the Dalai Lama wrote the forward so you may find it by googling neuroplasticity

Kate: Thanks Denise. I wish more was written by the pros but in lay language about the research. Maybe the MS Trust could look at this?

Simon - MS Trust: We had an article on plasticity in one of our newsletters a year or so back

Nikki - MS nurse: I don't remember this article, but thanks this is really good

Kevin: I have a big issue with fatigue - it's not a tiredness, it's you just so want to stop and lie down and have to.

Karaline: I agree, Kevin. For me the fatigue is not necessarily that I have to sleep, or that my muscles are exhausted. I just need to stop; to be horizontal.

Suzanne: I recognise that feeling. Not a winding down but a sudden, final, juddering halt with no warning

Jane - MS specialist: I've heard people with MS describe its as like hitting a wall or like my plug has been pulled!

Denise, MS clinical specialist: What you experience is really common. Earlier I mentioned idiopathic lassitude. As I mentioned previously, this is an overwhelming sense fatigue that comes on suddenly without warning and often without activity and sometimes even when resting. It's very difficult to combat and people describe it as hitting a brick wall. It often occurs in the afternoon and seems to coincide with our natural body clock, which wants to shut down at that time and send you to sleep. Ensuring you eat a snack mid afternoon is good as blood sugar dips then too after lunch. A power nap may help too. Pacing activities and balancing these with periods of rest can help. The MS Trust book on managing fatigue is really useful at explaining this and has lots of helpful tips from others.

Dagmar: I recently applied for - and received five weeks later - a London Taxi Card. I look upon it as a liberator and an insurance policy.

My reason for hoping to get a Taxi Card was that I hardly ever used to go anywhere because I was too worried that I'd suddenly be overcome by fatigue and would find it very difficult to get myself home again safely. Now I go out more often and I no longer worry about getting home.

I used the card twice in March (I had overdone it and suddenly run out of steam, and how very grateful I was to have it!) but not since. It seems that it's enough to know that I have it in case I need it.

If you think you would benefit from having a Taxi Card, obtain an application form from your Council, ask your doctor to sign it and GOOD LUCK

Suzanne: Cool, just googled Taxi Card for my area and a scheme came up!
Thanks Dagmar

Jane - MS specialist: It may be worth finding out from local councils what else is out there to help with transport. Access to Work is another good resource that can help with travel to work amongst other things and this can really help with fatigue at work

Karaline: What is a Taxi Card?

Simon - MS Trust: The London Taxicard website describes the scheme as "subsidised door-to-door transport in taxis and private-hire vehicles for people who have serious mobility or visual impairment". As Suzanne says, there are schemes in different places around the country. I think they operate differently too, so worth contacting your council to see what happens where you are

Suzanne: What do people think of oxygen tank therapy? I know people who have tried it and say it helps their fatigue for a few days. Others who haven't had that effect. Anyone tried it?

Denise, MS clinical specialist: We are lucky to have a Therapy Centre in Milton Keynes with a tank. A lot of my patients have had treatment and found it has helped their fatigue

Simon - MS Trust: MS Therapy Centres, many of which have oxygen tanks, are shown on the map of MS services on the MS Trust website

Frank: Jennifer tried the hyperbaric treatment. I think there was some slight improvement - she seemed to be more bright eyed and interested. However, particularly at the start, it is very time consuming and boring. Given the limited time and energy available, getting to and back from the tank as well as the time sitting in it wasn't worth the gain.

Denise, MS clinical specialist: Has anyone tried any other complimentary therapies for fatigue?

Kate: I use reflexology and shiatsu and yoga therapy for the overall management of the different things MS does to me. I'm quite strict with diet. I also use Emotional Logic to deal with emotional aspects.

Edward: Kate, since you use reflexology, what do you think of EMS - electrostimulation of foot points?

Kate: I have not heard of electrostimulation of foot points, Edward. I've been working with the same reflexologist for over 10 years and she was a nurse but is trained in massage and other therapies, so before doing reflexology she also does some work on my legs which helps keep me mobile and my legs more comfortable

Edward: EMS stands for muscular electrical stimulation. You can google it to see the apparatus - several different models and on-line shops. There are foot pads which will send electrical impulses into just about any point available! The idea is to promote blood flow in the legs as well as do all the reflexology and acupuncture foot points

Kate: Thanks, I'll look it up

Edward: Sorry, it's electro-muscular not muscular electrical!

Graham: I find that when I get fatigued my thinking goes fuzzy too. Presumably the two are connected? Is it also true that thinking in itself can be fatiguing?

Jane - MS specialist: I think you're right - fatigue can effect your thinking and cognitive processes and cognition can be tiring! Processing complex information and making stressful decisions can contribute to fatigue

Denise, MS clinical specialist: Graham, yes to both questions. It's useful to try to schedule any mentally taxing tasks that you need to concentrate hard on at a time when you know you are least fatigued. For some people this is mid morning. Also, ensuring that you don't get distracted and doing one task at time rather than trying to multi-task is easier. Often this mental or cognitive fatigue is also accumulative over a period of time, so you may feel you have even more difficulty as the day goes on or after repetitive cognitive task.

Simon - MS Trust: There is a website about cognitive symptoms in MS - concentration, attention span, memory - called StayingSmart (www.stayingsmart.org.uk)

Suzanne: I find it helps to rest mentally as well as physically. Sitting down with a cup of tea and watching telly for five minutes isn't a rest for me - I need to close my eyes and cut out noise and stimulus and empty my mind for a while

Denise, MS clinical specialist: I'm not if anyone has asked about heat and fatigue. I guess because we haven't hit the summer yet it isn't an issue that springs to mind. People often report to me that the hot weather wipes them out. When your core, central body temperature is increased, even if only by half a degree, it can exacerbate MS symptoms and especially fatigue. This also common if someone has a temperature caused by an infection such as a chest infection, cold, urinary tract infection. Is anyone here heat sensitive in this way?

Graham: Heat affects me, yes - can't think, can't move - dreadful

Kate: Yes heat affects me. I use a cool vest to reduce core body temperature and find that helps a lot. I got mine from www.soo-cool.co.uk

Fenella: My physiotherapist suggested something called a Chillow (type of pillow and they have their own website). It's great, especially at night when it is hot. Fab under burning feet. I've really enjoyed this chatroom as a technophobe. I've learned a lot from comments today and found it a relief that I am not alone with fatigue in MS.

Kate: I agree about Chillows. I wouldn't like to be without it when wake up with burning feet at night

Ruth: Oooo, I like the sound of the Chillow especially as, despite being only 46, I am in menopause as well as having MS so don't know which is causing night flushes but would welcome something that helps. I need my sleep!

Frank: Jennifer is badly affected by warm weather. It seems particularly deflating and energy sapping. However, I have yet to find her body temp too high - hers are the last feet I'd want to cool down. She feels cold, wearing lots of clothes coats etc

Denise, MS clinical specialist: There are lots of cooling gadgets out there - scarves, wrist bands, vest, body sprays and even whole body suits! The chillow does sound great. Simple things like taking a flask of ice with you when your out and about or to use at work are just as effective. Limiting hot meals can help too. And air conditioning, hand fans etc

Ruth: I was diagnosed with relapsing remitting MS last year. Having previously been very energetic and physically active, for the last couple of years I have had severe fatigue problems. Undoubtedly, doing too much makes me very tired. However, I think there is also a link between depression and fatigue. Just reading the comments in this chatroom has saddened me and I feel more tired now than when I started. Mental effort seems to induce fatigue as well as physical exertion. How should I manage that?

Jane - MS specialist: You may find it helpful to try a fatigue diary to get more of an idea as to what triggers your fatigue. Bear in mind what Denise was saying earlier about mental effort and trying to timetable in any difficult mental or cognitive tasks as well as trying to pace yourself through physical activities

Ruth: I do often make a note of when exhaustion hits me. The difficulty I have is that I have no regular pattern to my days/weeks (apart from taking medication at 8am, 2pm, 8pm and injecting Rebif on Monday, Wednesday and Friday evenings). I don't have a regular work pattern being an actor, so It makes it hard to plan/predict the need for rest time.

Jane - MS specialist: Sadly any of the 'girlie' stuff - periods or menopause - can make any MS symptoms worse and that will include fatigue

It's not easy when other things dictate how you use your time, but trying to see a pattern and trying to identify when you are at your best and planning around this may help gain a slight sense of control

Ruth: Do you mean it is possible that the menopause triggered the attack I had last year which led to my diagnosis? (given that I would have had MS for much longer undiagnosed)

Jane - MS specialist: re: menopause, I was suggesting it could make your symptoms worse (this is speaking generally without knowing what type of MS you have or your situ in detail)

Karaline: I have no regular pattern to my day or week either, but do find it helps to stay aware of what is happening in my body and if (when) I feel a tiredness start to come on, stop and take a break immediately for 5-20 minutes, rather than try to push on through it. Its hard if you are out and about, and sometimes I must look like a beggar sitting on a the ground leaning against a wall if that's all I can find to relax, but hey - it I don't then the fatigue can knock me back for days

Simon - MS Trust: We're coming up towards the end of today's session. Does anyone have any final questions?

Nikki - MS nurse: It's been good to read many of your comments since leaving the site for my clinic. Lots of excellent advice and food for thought

Nessie: Thanks to all who I've chatted with - all that you say makes sense. Especially the one about girlie stuff from Jane. Double whammy for me as I've been experiencing both and never know what to blame. Think I'm coming to the end of menopause if there is one having started early, but who knows.

Been a tiring sort of day for me and still feel punch drunk. Done a few jobs and off to do some cleaning up to try to kick start my body somehow. I need 50p for my meter - wish I could fid one sometimes lol.

Simon - MS Trust: Thanks Nessie. Next one will probably be September/October time. No topic yet, but watch the chatroom page for info

Nikki - MS nurse: Thanks for all the stimulating chat

Edward: Not a question, just a thank you to all the experts

Karaline: Cheerio and thanks experts and everyone

Jane - MS specialist: Thank you everyone for contributions

Frank: Ta lots..

Denise, MS clinical specialist: Thanks to all, it's been fun as always

Simon - MS Trust: OK, thank you everyone for a really good chatroom. Thanks to Michelle earlier in the day and to Jane and Denise and Nikki this afternoon. And especially to everyone who's shared their questions, experiences and thoughts. I hope it's been helpful. The transcript will be posted in a week or so and the next session will be in the autumn.

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

MS Trust Information Service - 01462 476700 / infoteam@mstrust.org.uk

Books

- At work with MS
- Disease modifying drug therapy
- Living with fatigue
- MS and me - a self-management guide to living with MS
- MS explained
- Primary progressive MS exposed (due to be published later in 2010)

DVD

- Move it for MS (an DVD of exercises led by Mr Motivator) - £1

Factsheets

- Diet
- FES - functional electrical stimulation
- Pregnancy and parenthood
- Vitamin D

Website resources

- A day in the life of an MS nurse - www.mstrust.org.uk/msawareness/educationqanda.jsp
- A to Z of MS - www.mstrust.org.uk/atoz
- Exercises for people with MS - www.mstrust.org.uk/exercises
- Map of MS services - www.mstrust.org.uk/information/services/
- Baby, MS and Me Blog - www.mstrust.org.uk/interactive/babymse/
- Staying active - www.mstrust.org.uk/stayactive

MS People UK email discussion list

- For more information visit www.mstrust.org.uk/mspeople

Facebook

- Find the MS Trust's groups at www.mstrust.org.uk/interactive/socialnetworks/

StayingSmart - www.stayingsmart.org.uk

a web-based resource designed by the MS Trust for people who want to know, or know more, about how MS can affect thinking

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

- Staying cool with MS - August 2007 p 11
- MS and yoga - May 2010 pp 8-9

Way Ahead article (Way Ahead is the MS Trust's newsletter for health and social care professionals)

- Imaging brain plasticity in multiple sclerosis - Way Ahead 2008;12(4):8-9

Contact the MS Trust to order publications or to join the Open Door mailing list. All publications are free apart from the DVD, which costs £1

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

Other resources mentioned

Charities

- **MS Society**
0808 800 8000 / www.mssociety.org.uk
 - MS Essentials 11: Diet and nutrition -
 - MS Essentials 14: Fatigue
 - MS Society branches - www.mssociety.org.uk/branches/index.html
- **Action For ME**
A charity for people affected by ME or Chronic Fatigue Syndrome (CFS)
0845 123 2314 / admin@afme.org.uk / www.afme.org.uk
- **Dystonia Society**
Charity for people affected by dystonia, a neurological movement disorder
0845 458 6211 / www.dystonia.org.uk
- **Net Mums**
online parenting organisation whose members are mostly mums
www.netmums.com
- **Riding for the Disabled Association**
Offering opportunities for disabled people to ride horses
0845 658 1082 / www.riding-for-disabled.org.uk
- **Rocky Mountain MS Center**
Based in the USA, has information on complementary and alternative approaches to multiple sclerosis
info@mscenter.org / www.mscenter.org

Other organisations

- **Access to Work**
Support for people with health or disability problems in the workplace. Can help employers with extra costs which may arise
 - London - 020 8426 3110 / atwosu.london@jobcentreplus.gsi.gov.uk
 - Cardiff - 02920 423 291 / atwosu.cardiff@jobcentreplus.gsi.gov.uk
 - Glasgow - 0141 950 5327 / atwosu.glasgow@jobcentreplus.gsi.gov.uk<http://tinyurl.com/accesstowork>
- **Jobcentre Plus**
Services include Disability Employment Advisors (DEA) to help people with a disability find a job or remain in work
0845 6060 234
DEAs - <http://tinyurl.com/disability-employment-advisors>
Jobcentre Plus - <http://tinyurl.com/jobcentreplus-contact>
- **Disability Law Service**
Providing legal advice and support for people in England with a disability
0207 791 9800 / advice@dls.org.uk / www.dls.org.uk
- **London Taxicard**
Subsidised taxis for people who have serious mobility or visual impairment. Similar schemes are operated by a number of local councils across the UK
0207 934 9791 / taxicard@londoncouncils.gov.uk / www.londoncouncils.gov.uk/taxicard

Commercial organisations

- **Breathworks**

Company providing training courses for developing mindfulness to help people cope with health issues such as pain and stress
0161 834 1110 / info@breathworks.co.uk / breathworks-mindfulness.org.uk

- **Emotional Logic**

Company offering resources and coaching in self-help and personal development
08453 709706 / office@emotionallogiccentre.org.uk / www.emotionallogiccentre.org.uk

Cooling products

- **Soo Kool**

Products available include Kool Ties and the Chillow
01535 274588 / rae@soo-cool.co.uk / www.soo-cool.co.uk

- **Chillow**

Marketed by Soothsoft Ltd
08700 117174 / info@soothsoft.co.uk / www.chillow.co.uk

Publications

- National Institute for Clinical Excellence.
Multiple sclerosis - management of multiple sclerosis in primary and secondary care. NICE Clinical Guideline 8.
London: NICE; 2003
- Allen Bowling
Complementary and alternative medicine and multiple sclerosis. 2nd edition
New York: Demos Medical Publishing; 2006
- Allen Bowling & Thomas Stewart
Dietary supplements and multiple sclerosis: a health professional's guide
New York: Demos; 2004
- Christine Miserandino
Spoon theory
<http://tinyurl.com/ybn8a6z>

References

Hericium

- Mori K, et al.
Nerve growth factor-inducing activity of hericium erinaceus in 1321N1 human astrocytoma cells
Biological & Pharmaceutical Bulletin 2008;31(9): 1727-1732.

Lipoic acid

- Salinthon S, et al.
Lipoic acid: a novel therapeutic approach for multiple sclerosis and other chronic inflammatory diseases of the CNS.
Endocrine, metabolic & immune disorders drug targets 2008;8(2):132-142.
- Yadav V, et al.
Lipoic acid in multiple sclerosis: a pilot study.
Multiple Sclerosis 2005;11(2):159-165.

Carnitine / acetyl L-carnitine

- Tejani AM, et al.
Carnitine for fatigue in multiple sclerosis.
Cochrane Database of Systematic Reviews 2010;2:CD007280.
- Famularo G, et al.
Carnitines and its congeners: a metabolic pathway to the regulation of immune response and inflammation.
Annals of the New York Academy of Sciences 2004;1033:132-138.
- Tomassini V, et al.
Comparison of the effects of acetyl L-carnitine and amantadine for the treatment of fatigue in multiple sclerosis: results of a pilot, randomised, double-blind, crossover trial.
Journal of Neurological Science 2004;218(1-2):103-108.

Brain training

- Owen M, et al.
Putting brain training to the test.
Nature 2010 Apr 20. [Epub ahead of print]