



# **Fatigue**

## **Chatroom**

**10 June 2004**

**[www.mstrust.org.uk](http://www.mstrust.org.uk)**

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**10 June 2004 – 10am to 7pm**

The experts:

- **Sarah Broughton**  
*Occupational therapist (10am-1pm)*
- **Sarah Winters**  
*Occupational therapist (1.30pm-5pm)*
- **Val Box**  
*Expert patient tutor (3pm-7pm)*
- **Gail Townsend**  
*Occupational therapist (5pm-7pm)*

**Simon - MS Trust:** Hello Chet, do you have a question?

**Chet:** I wanted to talk about tiredness. Some afternoons I feel very tired. Driving has become dangerous - I can easily fall asleep. It has become worse with the warmer weather too. Is there any medication?

**Sarah B - OT:** Can you be more specific?

**Chet:** I just become tired during the afternoons, I have got a very simple life too.

**Sarah B - OT:** You need to discuss with your neurologist whether amantadine might be helpful if you wish to try medication.

**Chet:** What does it do?

**Simon - MS Trust:** Amantadine has been found to work on fatigue levels and is covered in the recent National Institute of Clinical Excellence (NICE) guidelines. Another drug, modafinil, works on sleepiness - though this is not the same as fatigue. Both are part of a range of management that may include other things such as occupational therapy and physio.

**Chet:** OK, I will speak to my doctor about it. I'm not too sure what my problem is - sleepiness or fatigue. What's the difference?

**Simon - MS Trust:** Fatigue is a lack of physical and/or mental energy that interferes with daily activity and is out of proportion with any activity undertaken. It is more than just sleepiness

**Chet:** I only suffer from sleepiness, I have a lot of energy

**Simon - MS Trust:** Is there something that's interrupting your sleep or some other cause that means you are not getting the rest you need?

**Chet:** My sleeping patterns are weird. I sleep from 2am to 8 and then a two hour sleep in the afternoon. Could it be I'm not getting enough sleep at night?

**Simon - MS Trust:** Is there a reason why you don't sleep longer at night?

**Chet:** I can't get to sleep till about 2 and my work starts at 8am. I hate waking up late and missing the morning

**Sarah B - OT:** Can you be more specific why you cannot sleep?

**Chet:** I just feel tired till late, I think the sleep in the afternoon is the reason

**Sarah B - OT:** Have you thought about having a rest in the morning and a shorter rest in the afternoon?

**Chet:** Again, I don't feel tired till about 3 or 4 in the afternoon. Could it be that my sleeping pattern is out of order?

**Sarah B - OT:** I would maybe try and have a rest before you feel fatigued.

**Linda:** I have been prescribed Modafinil, but I do not really suffer from sleepiness, just extreme exhaustion.

**Simon - MS Trust:** How do you find it?

**Linda:** It gave me headaches at first, made me more tired. Just a few minutes of any physical activity leaves me on the point of collapse

**Linda:** I shall give Modafinil a bit longer (until I see my neurologist next week) but I am not impressed so far

**Chet:** I'll try just resting in the early afternoon

**Linda:** If I tried to rest before I become fatigued I would never do anything! It only takes a few minutes of activity to exhaust me

**Sarah B - OT:** Linda, have you tried to manage your fatigue with energy conservation techniques rather than just medication?

**Linda:** I try to sit down to do most things, and I HAVE to rest as soon as I feel tired or I would just sink to the floor

**Sarah B - OT:** Other energy conservation techniques are planning ahead, pacing activity eg resting before becoming exhausted, setting priorities of activities.

**Ali:** Hi. My mom has MS and suffers with fatigue quite a lot. Any suggestions how to lessen it? She isn't on any medication other than gabapentin. Should she just give in to it and go back to bed or is there anything else we can do?

**Sarah B - OT:** Ali, there are certain energy conservation techniques that your mother might find helpful. I can list them if that would be helpful.

**Ali:** That would be good

**Sarah B - OT:** Balance rest and activity, planning ahead, pacing, prioritisation of activities and taking a certain amount of exercise.

**Ali:** What is modafinil Linda talks of?

**Simon - MS Trust:** Modafinil is a drug that was developed for use in narcolepsy. It has recently been licensed in the UK for use with fatigue. It works on excessive sleepiness rather than fatigue, although there is a certain amount of overlap.

**Ali:** Oh yes I've heard of that but is it now licensed in this country?

**Simon - MS Trust:** Yes, it received its licence at the start of 2004.

**Mike:** My walking problems have barely changed in eight years, and fatigue has always been my main problem. But the fatigue has worsened. I now feel weary and weak from not long after getting out of bed. Is this a normal progression?

**Sarah B - OT:** Has anything else changed recently eg change of medication, life event, sleep pattern etc?

**Mike:** Now on blood pressure tablets, and sleep not as good lately

**Sarah B - OT:** Everyone is an individual. Another reason could also be that the weather has changed recently and you could be affected by the heat.

**Mike:** It came on two months so before the heat

**Sarah B - OT:** I would recommend that you visit your GP to review your blood pressure tablets.

**Mike:** OK Sarah, I'll do that

**annhas4hw:** I used to get extremely fatigued, especially in hot weather. Much better since taking regular exercise at gym.

**Ali:** do you have any other techniques my two sisters still live at home and are more hindrance than help any suggestions?

**Mike:** I can understand muscles tiring quickly and more easily. But why total fatigue without exertion (it's too much trouble to even feel like talking)??

**Sarah B - OT:** There are different types of MS fatigue. Short circuiting fatigue, which occurs when you can become fatigued after an activity, and lassitude, which is fatigue which can appear without being caused by a specific activity.

**Geoff:** Someone mentioned going to a gym. How does exercise help fatigue? Doesn't it make it worse?

**Simon - MS Trust:** There have been a number of studies that show exercise can help. MS can lead to people leading a less active life and this deconditioning can cause an increasing spiral of fatigue

**Chet:** I think I suffer from lassitude fatigue. I feel that swimming helps and makes me feel much better, it also helps my walking considerably

**Simon - MS Trust:** Gentle aerobic exercise (not taken to exhaustion) can help improve fatigue levels

**Geoff:** Thanks, and thanks Chet

**Chet:** And the worst thing is smoking. Cigarettes make my walking VERY bad and increase tiredness so I've stopped. Thanks for your help, and will speak to the doctor soon about medications

**Nick G:** As my hands are starting to hurt now, is it possible I am getting arthritis?

**Simon - MS Trust:** Nick - it's hard to tell. It may be due to MS, or something secondary - positional problems leading to problems with your hands. Or it could be arthritis or some other cause

**Simon - MS Trust:** Probably best to talk to your GP to investigate what's causing the problem

**Nick G:** Thanks for that. I will

**Nick G:** Chet, I was just going to say good on you for stopping smoking

**Mike:** Is there anything to give a kick-start when suffering lassitude? Any drugs to make me feel alive instead of existing?

**Sarah B - OT:** Mike, the two main drugs are amantadine and modafinil, which you need to discuss with your GP and/or Neurologist.

**Mike:** Modafinil made no difference to me

**Sarah B - OT:** Then maybe discuss with your GP whether amantadine would be helpful.

**Mike:** Yes, also tried amantadine but couldn't remember the name

**Sarah B - OT:** I would recommend that you try energy conservation techniques to see if it helps eg planning ahead, prioritisation of activities, pacing.

**Mike:** I think weight may be making things a bit worse. I gained stone and a half in six months (stopped smoking) was it worth it? lol

**Sarah B - OT:** Mike, well done for giving up smoking but maybe need to carry out some exercise - particularly aerobic - to help manage your weight and fatigue.

**John P:** I have stopped smoking after 30 years and feel better for it

**Simon - MS Trust:** Good for you, John

**annhas4hw:** I think deconditioning fatigue can be a huge problem - and folk don't always realise that's what's going on. Once I worked out what was going on (less activity, leading to more fatigue, leading to less activity) I found exercising at the gym a HUGE benefit!

**Geoff:** What exercises do you do?

**annhas4hw:** I use most of the equipment - within my ability

**Sarah B - OT:** Geoff, can I recommend you see a physiotherapist to advise on the best form of aerobic exercise.

**Geoff:** Thanks, Sarah. I'd like to do something but not sure what I can nowadays

**Mike:** I've recently started some gym work (bike, rowing machine, and upper body machines). Is that suitable?

**Sarah B - OT:** I am an OT so the best person to speak to is a physio but your choice, particularly upper body machine, might be too much. The advice on exercise is mainly to stick to aerobic.

**Geoff:** annhas4hw, do you use adapted stuff or is it working with whatever's in the gym?

**annhas4hw:** Whatever is in the gym. I cannot walk unaided so use 3-wheeled walker to move between things. Then sit on leg/arm exercisers. I can use recumbent bike and treadmill because rails/handles for support. Are you considering something like using gym, Geoff?

**Geoff:** Not sure what yet, but think I may be using MS as an excuse to be lazy :)

**annhas4hw:** Can happen Geoff! But fatigue gives "good reason" to do as little as possible - which leads to deconditioning, which leads to more fatigue. I found best answer was to do some enjoyable(?) exercise! Made me feel - and get - fitter!

**Simon - MS Trust:** The MS Trust is working on putting something together to help people with MS find sports and activities. Have a look at the transcript of the last chatroom we did on staying active with MS (transcripts at [www.mstrust.org.uk/chat](http://www.mstrust.org.uk/chat))

**Geoff:** I'll have a look. Disguising exercise as something interesting will help me :)

**Mike:** Deconditioning is a new phrase to me, can you explain it please?

**annhas4hw:** It is what happens to everyone if they don't take exercise - healthy muscles become unfit if they are not used. And people with MS need to preserve what muscle strength they have!

**Sarah B - OT:** This is when your body has become used to not taking exercise and the muscles may atrophy.

**Mike:** Atrophy?

**Sarah B - OT:** Atrophy is muscle wasting

**Mike:** Thanks both. Ann can I ask if you are still mobile after 30 years? It would be a real encouragement

**annhas4hw:** I am "normally mobile" from the waist up! Can walk very short distances with two sticks. I use a wheelchair a lot in house, as cannot do much with stick in each hand! I am locally mobile on electric scooter. I drove "normally" until about three years ago and recently started driving again with hand controls.

**Mike:** Ann how long before you needed aids?

**Mike:** are we talking 20yrs walking Ann?

**Rosalyn:** Hi Ann. I have been using one stick but now trying two. The damn thing is I keep falling. I am waiting for the OT to bring a frame

**Julie:** I've just been doing some gardening and am now shattered - as always, it's difficult to pace accurately. Any suggestions?

**Sarah B - OT:** Try and rest before you become exhausted, take time out for five or ten minutes during an activity, sit down for some part of the activity, balance the type of gardening

**John P:** What do you suggest to overcome excessive heat and resulting exhaustion. Paracetamol?

**Sarah B - OT:** John, have you thought about fans or a cooling system in your home. Paracetamol will only work for a temperature due to an infection.

**Rosalyn:** I am very interested in find out about heat I have trouble with that

**Julie:** John, I find that in extreme heat to lie in a tepid bath for a while helps cool me down and thus energise me again

**Sarah B - OT:** Rosalyn, some people find thinking about their diet, use of fans, cool baths/showers can help.

**Linda:** My husband came home on Monday with an air conditioning unit - just in time for out 31C on Tuesday. Just sat with it blasting on me all day- bliss

**Rosalyn:** Cool baths and showers do help but diet how does that work?

**Simon - MS Trust:** Prior to the session a dietician sent in a comment on diet and fatigue, which is relevant here. "Don't forget that neglecting your diet can add to fatigue. By eating a balanced diet, and not missing meals this maximises the nutrient supply to your body to help you cope with fatigue. Try to achieve a healthy weight - being obese, or underweight can increase fatigue. Some people rely on sugar boosts such as sugary drinks or snacks to increase energy levels – the disadvantage of this is that these foods are absorbed rapidly, leading to an increase in blood sugar. This triggers the body to make more insulin to bring the sugar levels down again, so blood sugar levels then fall, leading to a 'low' feeling again. These 'highs' and 'lows' can be avoided by taking longer release starchy foods, such as fresh fruit, cereals or sandwiches. Between meal snacks may be helpful if you have a long gap between meals."

**John P:** A couple of days ago I had a very bad experience collapsing in the high heat - probably the best thing is not to go out and keep cool at home

**Linda:** I find that I rarely feel hungry, and after a few mouthfuls I struggle to eat any more. After a course of steroids in April I suddenly had an appetite again for a few weeks

**Sarah B - OT:** You might find it helpful to see a dietician. Your GP should be able to refer you.

**Linda:** OK, I'll ask her

**Rosalyn:** Yes I am being careful to eat little and often as I am trying to lose weight but I find that I get dizzy with heat. Can diet help that?

**Sarah B - OT:** You might be not having a well balanced diet, also maybe think about timing of your meals.

**Rosalyn:** Thank you Sarah, I will look into the timing

**John P:** Goodbye everybody - going for a rest so I can go out later for a beer!

**Simon - MS Trust:** Bye, John, thanks for your input. Enjoy your beer

**Julie:** I find the biggest problem about fatigue is that others don't understand it

**Chris:** Do you find too much sleep can cause fatigue?

**Sarah B - OT:** I suppose it depends what else you are doing in the day, we recommend having rest during the day and balancing rest and activity.

**Paul:** Sarah, I often have trouble sleeping which makes me tired for the following day. Is this typical of MS?

**Sarah B - OT:** People often express difficulty sleeping, can you identify a reason why?

**Paul:** I get muscle contractions in my right leg. Not painful but very annoying. They keep me from sleeping.

**Mike:** Would baclofen be of any help to Paul?

**Simon - MS Trust:** Paul, do you take anything to help with the spasms?

**Paul:** No, I try to avoid drugs if at all possible. My MS is mild so I can do that so far, but any non-drug approaches would be handy.

**Simon - MS Trust:** Have you noticed anything that triggers the spasm, such as the position you lie or the weight of the bedclothes?

**Sarah B - OT:** Another thing in relation to spasms in bed is to think about positioning and a physio can help.

**Paul:** I find the spasms are worse when it's hot like now in the summer. I often leave my leg out of the covers but that doesn't work!

**Simon - MS Trust:** It may be worth trying to talk to a physiotherapist about ways to avoid spasms

**Rosalyn:** I find the physio makes me bad as its too long

**Simon - MS Trust:** You need to make sure the physio knows when you get to your limit and that over-exertion can make your fatigue worse

**Ellie:** I am having to do physio with the cardiac rehab team having had a heart attack. It is circuit training, and I find it very hard

**Paul:** I often have a nap in the middle of the day - I find it helps a lot - but it's not so good if you have to do something.

**Rosalyn:** They do not listen. When I said I wanted to avoid Mondays as I wanted to go swimming the physio said do not be silly you can do both

**Sarah B - OT:** What are you going to physio for specifically?

**Rosalyn:** I am going to the physio because my GP told me it was the only way to keep walking

**Sarah B - OT:** Maybe try and discuss your fatigue with your physio and how you manage this. We would recommend balance of activity. Maybe she has not taken this on board

**Rosalyn:** Thank you Sarah, will do

**Paul:** I think the physio is good - it just takes so much discipline to do the exercises.

**Simon - MS Trust:** Do you do physio as part of a group?

**Paul:** No, I see a physio in the hospital - never the same one - but they are good and helpful. I will talk to the physios about night spasms - it would be great if I could do exercises to get rid of them - I never thought of that.

**Simon - MS Trust:** It's more about positioning and posture than exercises necessarily, but a physio may be able to offer some help

**Jo:** I find the breathing and gentle stretching of yoga useful, and can be done lying down

**Nathalie:** I've recently started yoga too. I find it very helpful against tension and anxiety that stops me sleeping. It took me a long time to find a class that suited me though. Some were horrible

**Simon - MS Trust:** Several people in a previous chatroom said they found pilates helpful

**Nathalie:** I did Pilates too for about 3 years. Felt like a change. It's good for strengthening, but less for relaxation.

**Jo:** yes the physio was helpful in getting me to put my legs in a better position, including support with a tempur pillow

**Jo:** Yes, Nathalie, the approach of the teacher makes a big difference. I've had contact with the Yoga For Health Foundation in Bedfordshire. They have lots of experience working with MS

**Nathalie:** That's useful to remember.

**Paul:** I'm really keen to do yoga with a specialist MS yoga teacher - does anyone know one in North London?

**Jo:** Contact [yogaforhealthfoundation.co.uk](http://yogaforhealthfoundation.co.uk). They have a list of teachers they have trained. I think you should ask if they have done the remedial yoga training as well as the teacher training

**Paul:** Thanks Jo - I will do that

**Ellie:** Sarah, what is your opinion of tempur mattresses and overlays to aid comfort and help with sleeping for those with pain and spasm?

**Sarah B - OT:** I think with any form of equipment you need to trial it. Some people find some mattresses helpful but others will not.

**Paul:** What is a tempur Mattress?

**Ellie:** Visco elastic stuff used in space ships, heat reactive and moulds to the body, very expensive

**Jo:** I was thinking of getting one, but was told by a chiropractor that they retained body heat and so not good if affected by that

**Ellie:** I wondered about that. I have a pillow, not tempur, a bit cheaper but the next one down the financial scale. It is great, and I don't get a hot head

**Mike:** So at least we established Ellie isn't hot headed, lol

**Ellie:** lol

**Geoff:** What is tempur?

**Sarah B - OT:** Tempur is a mattress made from visco-elastic which is a temperature sensitive material with an open cell structure. Some people find them helpful some don't. Need to trial before purchase.

**Nathalie:** I've been researching the use of histamines to help fatigue. What's anyone's opinion? I don't like the idea of the combined caffeine/histamine patch as caffeine and I don't mix well.

**Simon - MS Trust:** Nathalie, the histamine/caffeine patches are called Prokarin.

**Nathalie:** I know. As I said, I don't like the idea of the caffeine. Is straight histamine available? Has anyone tried it?

**Simon - MS Trust:** There was a small trial published in 2002 that found 'a modest effect of Prokarin' and that the effect was more than of just caffeine alone. The paper called for a larger trial, but as far as I know, nothing has happened yet

**Paul:** I have be told that Prokarin is very expensive

**Rosalyn:** Ann, you were talking about your MS earlier. I was told I have progressive MS last year I got the impression in about 5 years I will be unable to even get out of bed. I was wondering how you get on. It would be nice to know that after 30 years I could still walk. Sorry is that rude?

**Ann:** The progression of my MS has been slow - diagnosed December 1979 when our children aged 1 and 5! Lived normal active life throughout their childhood - helped at playgroup, took them camping. Did get fatigued while walking, ran out of energy easily - but generally kept up well enough - went back to work when they were 9 and 13 (1988).

**Rosalyn:** Oh great that's just what I need to hear I still trying to get my head round this MS thing. I felt progressive meant that it was the end

**Ann:** Worked (in an active job) for ten years - but WAS struggling a bit, with work, home and teenagers!!

**Rosalyn:** I think most mothers do

**Ann:** I remained on my feet for more than 20 years after diagnosis. Still can be on my feet - with 2 sticks, for short distances, but also using wheelchair.

**Rosalyn:** Thank you so much for talking to me, Ann. You may never know how much you have helped me

**Ann:** It may help you to know that I'm still active, though my legs not good now. BUT MS is different for everyone.

**Rosalyn:** I think MS being different for everyone is why my GP will not talk about it

**Simon - MS Trust:** Rosalyn, it may be worth contacting your nearest MS Society branch to talk to people there ([www.mssociety.org.uk/about\\_us/around\\_the\\_uk/](http://www.mssociety.org.uk/about_us/around_the_uk/)) Or there are online groups such as Jooly's Joint ([www.mswebpals.org](http://www.mswebpals.org)) or the MS People UK list (see [www.mstrust.org.uk/mspeople](http://www.mstrust.org.uk/mspeople))

**Rosalyn:** Thank you Simon I will do that

**Chris:** I find the fatigue the hardest bit to come to terms with, some days I have to really force myself to get out of bed

**Sarah B - OT:** Chris, how do you manage your fatigue?

**Chris:** I try to rest when it's possible but as you will all know this isn't always easy. I have enrolled at the local sports centre and I try and get there if possible but I've been unable to go for the last couple of months

**Sarah B - OT:** The important thing with fatigue is try different fatigue management principles of energy conservation techniques and to undertake exercise.

**Chris:** I don't do too much whilst there and if I find I'm getting too tired I sit and watch for a while. I try and walk on the treadmill at a reasonable pace and I aim for ten minutes I also do some resistance training using the weights but on the lowest settings

**Jo:** is there any research on ms fatigue and diet

**Simon - MS Trust:** I'll have to have a look for info in fatigue and diet

**Jo:** Thanks, I have to go soon, so how do I find your answer later

**Simon - MS Trust:** We'll be publishing a transcript of this session in a few days (after a little bit of tidying up)

**Simon - MS Trust:** Alternatively, send your email address to me at [info@mstrust.org.uk](mailto:info@mstrust.org.uk) and I'll get something to you

**Jo:** Thanks Simon - bye everyone

**Simon - MS Trust:** Thanks for your input, Jo

**Chris:** What confuses me is why I can't tolerate the hot weather we have in this country but aboard it is often hotter and I tend to tolerate it much better

**Sarah B - OT:** Maybe you are more relaxed on holiday and in hot weather here you very active in running daily life.

**Chris:** I think you may be right although I don't seem to do much physical work. If I vacuum, I need to have a long rest afterwards and usually go to sleep

**Linda:** I have been lucky enough to holiday in Australia and South Africa. I think the difference is that all shops and hotels have air conditioning so you are able to cool off regularly and don't get too hot

**Sarah B - OT:** I think that is a very good point. We don't cope with hot weather here very well.

**Simon - MS Trust:** I think the humidity can play a part too - some people find the dry heat in some places abroad isn't like the sticky heat we get here

**Linda:** I also went to Darwin where it is very humid, harder to cope with than drier place but still better than home

**Chris:** Yes, Simon, I think that is it. When I was on holiday I found I wasn't sweating like I do here, but that may be a disadvantage as perspiring is supposed to cool us isn't it?

**Simon - MS Trust:** It does seem to be different for different people, certainly. Although less frequent, some people with MS find cold has the same effect

**Linda:** I find the transition from cold to warm difficult in winter, coming back into a warm house

**Chris:** The cold - now that has started to affect me also. I never used to feel the cold much, never wore hats or gloves. Last winter I couldn't get warm and was wrapped up like an Eskimo

**Simon - MS Trust:** Did the cold make symptoms of MS worse, or was it feeling cold that was the problem?

**Chris:** It was the feeling of the cold where as the heat makes the pain and co-ordination much worse

**Simon - MS Trust:** As we seem to be in the lunchtime lull, maybe I should another comment from Bernice Chiswell, a dietician. "Some find that a 'heavy' meal in the evening can increase fatigue - eating small, frequent meals and snacks may be more helpful. For others, eating a small main meal at lunch time with sandwiches, etc, later in the day suits them better. Don't forget breakfast to provide energy and nutrients in the morning - studies have shown that people's mental performance is better if they have breakfast."

**Maggie & David:** Hello, I've logged back in now, and have my Dad on the end of the phone

**Simon - MS Trust:** Hi Maggie and David

**Maggie & David:** My Dad has primary progressive MS. He suffers from fatigue. At its worst he doesn't have energy to listen to the radio whilst lying down. He has two questions - can you suggest any fatigue management techniques and can you suggest ways of reducing fatigue when sitting in a chair (very uncomfortable and tiring).

**Simon - MS Trust:** Management of fatigue is primarily based on finding ways of managing life to lessen the impact of fatigue. This can involve strategies to avoid the build up of fatigue and to conserve energy. Management can involve a range of people. An OT can help with equipment and adaptations to save energy - both adaptations to the household environment and to the ways in which someone might approach tasks. A physio can help with building up strength, which can make it easier to handle fatigue. There are also drugs that can play a role, such as amantadine (for fatigue) and modafinil (which works on excessive sleepiness). Central to management is the person with MS and their awareness of the symptom - what makes it worse, how much they can do and when to rest to build up energy enough to do what they want to do.

**Simon - MS Trust:** Your second question about sitting in a chair - it may be worth trying to talk to a physio about posture. If posture is wrong, it can lead to discomfort and worsen fatigue. If you aren't getting much exercise, this can lead to the body becoming weaker and an increase in fatigue. Doing some gentle aerobic exercises might help counteract fatigue

**Maggie & David:** Thanks for the info Simon. Dad will review his posture in a chair next time he sees a physio. He has found physio very helpful, but found the physical effort of getting there to outweigh the benefits. He's recently managed to get a private physio to make house visits, however.

**Simon - MS Trust:** We've recently published a book of gentle exercises for people with MS that may be useful. Have a look at the publications list at [www.mstrust.org.uk/publications](http://www.mstrust.org.uk/publications)

**Maggie & David:** Is the book by Liz Betts called 'Exercises for people with MS' the one with gentle exercises?

**Simon - MS Trust:** That's the one. You can either download it from the site or email your address to [info@mstrust.org.uk](mailto:info@mstrust.org.uk) for the book itself

**Maggie & David:** I'll download the Liz Betts booklet, Dad hasn't seen that one. Thanks for your help, bye.

**Vicki:** Hi. The hot weather makes me very weak and tired. I have looked at cooling vests, but aren't they a bit impractical for work in the office? The MS nurse said that I should be referred to a 'neuro' physio, but there isn't one where I live. Could a 'normal' physio help me?

**Simon - MS Trust:** Vicki , neurophysios are quite few and far between. Many general physios will have experience of seeing people with MS and should be fine. It may be worth talking through your MS with them before you start sessions so that they are aware of what your limits might be and don't overstretch you

**Vicki:** Should I be at a certain 'stage' of MS before I would benefit from physio? I have good and then really bad days - but still mobile.

**Simon - MS Trust:** A few years ago, the MS Trust put together a book where we asked people with MS to tell us tips they would give to others with the condition. One of the striking features of the responses was the number who said do physio and do it from as early as you can. There are different exercises and interventions that may be applicable at different times, but it seems that general physio/exercising is important.

**Vicki:** I just didn't want to use up resources that weren't 'necessary' for me and that others more poorly could use. I do however want to fight this. I'm only 30.

**Simon - MS Trust:** That's not the case here - make the most of what's available

**Vicki:** Sorry, but I have one last question

**Simon - MS Trust:** Sarah Winters is an occupational therapist. She's just joined the chatroom, maybe she can help

**Vicki:** I have a chance to go white water rafting with work – teambuilding. My husband thinks it's not a good idea and my mom thinks I'd be mad? I want to go. Am I mad to consider it?

**Sarah W-OT:** Hello Vicki , What's your exercise tolerance like?

**Vicki:** Pre ms I use to go to the gym three or four times a week and run. Now I walk and swim. Heat kills me

**Sarah W-OT:** White water rafting will obviously be extremely strenuous. How many in the team? Do you all need to paddle?

**Vicki:** I'm not sure about paddling, but there will be at least four stropping men with me. (Lucky me!)

**Sarah W-OT:** Go for it. Sounds like great fun! Just monitor your fatigue levels in the days prior to going and limit your exertion.

**Vicki:** Hope my husband and mom can come round to the idea. Feel like I'm fighting against them. Have they written me off? Worried, I know.

**Sarah W-OT:** They are bound to worry. Explain to them why you feel it's important to you and be sensible - you know your body.

**Vicki:** Better go, lunchtime over. Thanks Simon & Sarah for your advice and support

**Simon - MS Trust:** A message sent in prior to the chatroom by Amanda. "I saw my neurologist today. He suggested that something called "cognitive fatigue therapy (?)" might be suitable for me if all other alternatives continue to fail to help with my MS fatigue. First he decided I needed to try a higher dose of amantadine, along with the pattern of rests I have already established thanks to OT. Can you tell me something about this cognitive therapy? Is it the same as general cognitive behavioural therapy or something different?"

**Sarah W-OT:** Not heard of cognitive fatigue therapy but do know about cognitive behaviour therapy. This is an approach that helps people identify, understand, and modify their belief systems and to examine their response to situations in order to function more effectively and happily. An individual can feel greater control over life and therefore reduce levels of stress/fatigue.

**Ellie:** Sarah, how do you go about this? I've heard of it but there are no groups round here

**Sarah W-OT:** Cognitive behavioural therapy would be provided through clinical psychology service. OT's use relaxation techniques to enable a reduction in stress levels.

**Ellie:** Yes I know what you mean. We have a clinical psychologist as part of the cardiac rehab service, and it all boils down to the same in the end – MS, heart attack; the reasoning is much the same.

**Martin:** Just something general really. How can an OT and physio help with fatigue?

**Sarah W-OT:** Hello Martin, OT can help with fatigue by advising on how you manage daily activities and how to adopt fatigue management strategies such as balancing rest and exercise prioritising activities, planning ahead, energy conservation tips.

**Ellie:** Has anyone come up with any medicines that help the fatigue

**Simon - MS Trust:** The NICE guideline only mentions amantadine. Since the guideline was published, modafinil has been licensed in the UK

**Ellie:** Oh, my GP said that was too expensive

**Simon - MS Trust:** Modafinil was developed for narcolepsy and works on excessive sleepiness rather than fatigue itself, but there is a certain amount of cross over

**Ellie:** I have enough trouble getting to sleep as it is, don't have narcolepsy. I'm not sleepy, just wiped out !!

**Kashy:** Sarah? You're an OT?

**Sarah W-OT:** Yes I am. Is there anything you'd like to ask?

**Kashy:** I'd just like to know the simple things - well things that were once simple that don't cost a lot of money

**Val:** Kashy, How do you deal with your fatigue?

**Kashy:** I don't Val, how do you?

**Val:** I guess I do a lot of pre-planning - for example today I am an 'expert' on the chat room and so I rested this morning

**Kashy:** I have a husband who will not accept that I have MS, which makes resting a no no. And I have kids

**Val:** I know that can be difficult. So do you rest while they are at school and work? Then I have to do the housework unless as luckily for the past few months I had a PA

**Sarah W-OT:** Have you ever thought of completing an activity diary, looking at your daily routines?

**Kashy:** I write a daily list and cross off the jobs as I do them

**Val:** I have just found a cleaner. She only comes for two hours a week but well worthwhile

**Kashy:** I had mine for 20 hours and I miss her so much

**Sarah W-OT:** It's useful to help prioritise what you need to do and then fit that around your times of fatigue rather than doing it all in one go

**Kashy:** I don't do it all in one go and haven't for some time. But when I feel the fatigue coming on, it comes without warning and I fall asleep wherever I am, - hairdressers, Morrison's, car etc

**Sarah W-OT:** Do you spread activities to be done over the week?

**Kashy:** I try Sarah, I feel I need more rest on a Monday after the weekend

**Sarah W-OT:** Do you do any relaxation?

**Kashy:** I don't get chance, if I try, I know I'll fall asleep within a minute. My children say I'm narcoleptic. Do you have children Val?

**Val:** That is interesting as the fatigue drug modafinil is also used for narcolepsy

**Kashy:** I'm on a lot of different drugs, but not modafinil

**Val:** No I do not have children and only a part time husband, ie weekends

**Kashy:** It's weird that it comes with no warning - in the middle of Corrie, lol. And I'm in bed for 8

**Val:** If you have no problem sleeping then maybe a little exercise would help the fatigue

**Kashy:** I'm way past exercise sadly

**Val:** It is possible to do hand and arm exercises if the legs are difficult

**Kashy:** Yes, I do those throughout the day. Thankfully I have strong arms at present

**Alison:** Hello. I am glad we are talking about fatigue today, as I think, I get fatigue!!

**Simon - MS Trust:** Why do you say you 'think' you have fatigue?

**Alison:** I am newly diagnosed, on 26th February, and have just started beta interferon. I have always been tired, but this is different.

**Sarah W-OT:** Alison, how do you manage your fatigue?

**Kashy:** Fatigue is 'nasty'

**Alison:** I just stop what I am doing for now. This is all new to me

**Val:** Yes, a study seemed to show that the fatigue of MS is worse than that of ME

**Kashy:** I have no choice in whether I stay awake or not, I just zonk out

**Val:** Also the level of fatigue does not relate to the type or severity of MS

**Kashy:** I have secondary progressive

**Alison:** Do any of you feel weak, and sickly when it happens?

**Kashy:** Yes, weak and just drained. Then my eyes just close in mid sentence when people are talking to me it happens

**Alison:** My right eye gets blurry too. Is this fatigue?

**Kashy:** That sounds just like mine, Alison. Mine has a waterfall in it, well it looks like that

**Val:** When you are fatigued the other symptoms of MS, eg vision, will worsen

**Kashy:** You are right Val

**Alison:** Yes, that's it!! I see things differently and can't clear it!

**Kashy:** And do you rub your eyes trying to see better?

**Alison:** Yes, but it makes no difference at all

**Kashy:** Yup, that's why I've not been at work since March.

**Val:** Heat often aggravates fatigue and so any ways of cooling down can help, such as fans or a good one is sucking an ice lollipop

**Kashy:** Now it's the cold that upsets me

**Alison:** Oh, I am sorry. I think I have a lot to learn yet

**Kashy:** Don't worry Alison, it'll hopefully be a long time off. I wanted to know if anyone had any helpful tips on ironing

**Val:** Was the fatigue your first symptom? I think it was for me

**Alison:** Tips on ironing, I do mine UNDER a ceiling fan!

**Kashy:** My first symptom was numbness in my leg

**Alison:** Eyes/headaches were my first symptom

**Kashy:** I can't even lift the ironing board to put it up - damn wheelchair

**Sarah W-OT:** It's useful to sit on a stool whilst ironing, in a cool room with good ventilation

**Kashy:** But it's so difficult to get any pressure on the iron

**Sarah W-OT:** The ironing board needs to be at a low enough height to lean your weight over it

**Kashy:** I seem to get a rush of adrenaline and can reach the tap to fill the iron, do a few hours, and then collapse later

**Val:** Do you really mean you iron for hours!!!! Ten minute bursts are all I do at a time

**Kashy:** I take a long time Val, because I'm so slow. About two or three times a week. I wouldn't get one shirt done in ten minutes

**Val:** Particularly for Alison, I have found fatigue to have lessened since diagnosis - six years ago - partly because I have learnt to say no

**Kashy:** I need to do that Val

**Val:** Yes you really have to practice assertive techniques. Some of my friends are now a little afraid of me

**Glenda:** Does anyone know of a good book or article giving info on strategies to cope with fatigue?

**Sarah W-OT:** A good booklet is Managing MS Related Fatigue by Lauren B Krupp

**Val:** Coping with MS by Cynthia Benz, published by Vermilion. Also both the MS Trust and MS Society have useful factsheets

**Glenda:** Many thanks for the info. That will be very useful to myself and colleagues

**Sarah W-OT:** What do you do?

**Glenda:** I work in Community Rehab and myself and my colleague offer a service to a wide patient group. We don't specialise in MS but both have an interest in the condition.

**Sarah W-OT:** Glenda, there is also a useful pack available for professionals to run fatigue management programmes. Has lots of info on fatigue and evidence based practice.

**Simon - MS Trust:** Remember that the MS Trust has an information service for both professionals and people with MS, so if we can help with anything, let us know. email [info@mstrust.org.uk](mailto:info@mstrust.org.uk) or ring 01462 476700.

**Sarah W-OT:** Kashy, are you seeing an OT?

**Kashy:** No, I have started seeing a physiotherapist

**Sarah W-OT:** That's good as exercise will help fatigue. Do you know if a fatigue management programme is running in your area?

**Kashy:** I've not heard of one Sarah. Where do I find that out?

**Sarah W-OT:** Do you have contact with a local MS nurse? They would know.

**Kashy:** Yes I do. I'll ask her, let me write that down

**Val:** Also the local physio or OT service might know

**Kashy:** Oh? right, that's really helpful

**Alison:** I have had more problems with fatigue affecting my mobility. This has lead to a broken ankle. The trauma has made the MS worse and with it I am less mobile with even more fatigue. What rehab do you suggest?

**Simon - MS Trust:** Are you seeing a physio?

**Alison:** I still have the cast on but they are talking of me seeing either an orthopaedic or neuro physio sometime when it is off. The neuro also talked about more pills but am very reluctant to take yet more

**Simon - MS Trust:** Building up your strength through physio and gentle exercise should help with the fatigue

**Alison:** The thing is I used to use a trike to get to and from town and so was taking loads of exercise but it still got worse.

**Simon - MS Trust:** It's important to be aware of limits and not exercise to exhaustion. Was this the case when you were on your trike?

**Alison:** I don't think so as the really bad days often came when I was tired after working. I really want to get mobile again and stay working. It is as if it is more mental than physical tiredness that affects me and I hate it when it makes my speech bad

**Val:** I wonder if you would consider a compromise - part time working. This is what I did after diagnosis and helps with the fatigue

**Alison:** I now only work 18 hours!!! But I am a single mum to two teenagers, so I guess that could contribute!!! lol :-)

**Val:** I have been diagnosed six years and better planning has made it more bearable. How is fatigue for you, Sharon?

**Sharon P:** I manage OK (ish) I tend to organise my day so that all physical work is done in the morning!

**Val:** Perhaps you could delegate particular tasks to your teenagers

**Alison:** I know, but like all kids they are VERY resistant to working in the house and cross that they have to do stuff because I am disabled. The trouble is that I don't drive so even simple shopping etc and getting about is extremely tiring I guess!

**Val:** One strategy is to list everything you do, then decide whether it is necessary, can be delegated to others, and what remains can be done on different days of the week or first thing in the morning

**Sharon P:** Alison, have you tried explaining to them that they would be doing you some good?

**Alison:** They have been better since I have been in hospital and the house is full of stair lifts, wheelchairs and grab rails

**Kashy:** Hello

**Val:** Welcome back Kashy. Were you having a power nap?

**Kashy:** lol Val

**Sarah W-OT:** That's good advice from Val. It helps you to prioritise what is important to you

**Alison:** Those really work don't they, the power naps

**Sharon P:** They do, if you can get some peace and quiet!! I'm living on a building site at the moment. The council is changing all the lampposts

**Alison:** I have been waiting two years while they plan our changes and am looking forward to an easier kitchen, shower etc

**Kashy:** Are you having a wheel in shower Alison?

**Sharon P:** Alison, is that the council?

**Alison:** No Kashy, only sink washes for the last two months and next month. But Cambridgeshire plans to do something sometime. But it may go on much longer because the OT says my shower and bath are now very dangerous

**Kashy:** Are you having a shower put in?

**Alison:** Yes, but the guy from the council is now talking of 2005!

**Kashy:** Well, Alison, it'll be so wonderful when you do get a shower

**Alison:** Can't wait. I was so lucky though because I got some carers for a short time after I got out of hospital who really helped. Kids love telling me if my feet smell though! It sort of changes the tables on me

**Kashy:** I last had a shower...can't remember when, but it was about a year ago

**Alison:** I have started to think that I must find level access showers in the city and visit the places just to wash! lol

**Kashy:** I tried that. I asked the doctor if I could go to the local hospital, but he said not possible

**Kashy:** Does anyone else have this symptom, people (family) speak to me and I hear and see them but I can't reply as I'm sort of asleep

**Val:** Yes, it sometimes seems impossible to communicate, but also they have learnt to recognise the certain look in the eyes

**Kashy:** My boys say I've lost the plot

**Alison:** Kids do find it hard don't they?

**Kashy:** They do lose patience quickly

**Alison:** If they are like mine they mean really well but actually changing habits, cups all over the place, bags dropped etc doesn't change

**Val:** Is it possible for your priorities change so that bags on the floor are acceptable and thus save energy for more important battles?

**Sarah W-OT:** There are a couple of books for kids to help them understand MS

**Kashy:** What are the books Sarah?

**Sarah W-OT:** They're called "My Mum's Got MS" and "My Dad's Got MS", written by the MS Society I think. MS Nurses will have copies

**Sharon P:** MS nurse? What's one of those!! ;->

**Simon - MS Trust:** Actually "My Mum" was published independently and "My Dad" was done by the MS Trust. Both can be ordered from [www.mstrust.org.uk/publications](http://www.mstrust.org.uk/publications). My Dad's Got MS can also be downloaded from the order form at that webpage

**Val:** There are about 150 MS nurses in the country. They usually work from the neurology departments and are very knowledgeable

**Alison:** I have to say that my MS nurses, first in Oxford where I was diagnosed and now in Cambridge have been WONDERFUL. During my 2½ weeks in hospital (broken ankle and an inaccessible house) the MS nurse was the one point of sanity

**Kashy:** Is there a book for spouses? I have found that although I've been diagnosed ten years, my husband just will not accept it. And as I get worse, the more he blocks it out

**Simon - MS Trust:** Not as far as I know, Kashy, but we have published things on being the partner of someone with MS in Open Door, our newsletter

**Sarah W-OT:** As part of the fatigue management programme that we run, partners are invited to last session, and this gives them a greater understanding of how fatigue affects a person with MS

**Val:** Kashy The MS Society run study days (usually on a Sunday) for people with MS and spouses, partners etc. I took my husband to an MS Society course. There were presentations and workshops. He learnt everything he wanted to know and could talk to other partners and let off steam

**Kashy:** Can I get a copy of that Simon? He would never 'go' anywhere, but he may read something

**Simon - MS Trust:** Follow the link to Open Door at [www.mstrust.org.uk](http://www.mstrust.org.uk) and look for A Partner With MS (Nov 2001). We hope to be running another article by someone whose husband has MS in a future issue. To go on the mailing list for Open Door, just email your postal address to [info@mstrust.org.uk](mailto:info@mstrust.org.uk)

**Kashy:** Thank you Simon. My kids try to understand, but my husband is in total denial - and I've been diagnosed ten years

**Val:** I think denial can be healthy in small amounts, but I guess you find it very frustrating. I think my husband needs reminding from time to time

**Kashy:** My husband can't accept what he calls 'people like me'

**Val:** I think my husband compensates when he has a virus and seeks help from the doctor. I was amazed he was given antibiotics last time

**Kashy:** I think it would be easier without husbands sometimes

**Val:** Would you be able to persuade your family to attend social events organised by your local MS Society or Therapy Centre?

**Kashy:** I doubt it, Val. I've tried in the past before I was in a wheelchair. What is a Therapy Centre?

**Val:** Most counties have a MS Therapy Centre. I belong to the Berks MS Therapy Centre. It is a charity

**Kashy:** What sort of things do they do?

**Val:** You can usually have physio and oxygen treatment, reflexology and other complementary therapies. Where do you live?

**Kashy:** Derbyshire. I've not heard of one here

**Val:** Nottingham, Leicester and Sheffield may be your nearest

**Kashy:** Well, my children are home, so I had better leave. Thanks all for your helpful info. Bye

**Sarah W-OT:** Bye Kashy - best of luck

**Alison:** I think the therapy centres are great but getting to them can be a great problem. I would love to do the oxygen but I have never lived near enough to one to go regularly and our local MS branch is about to stop its transport to the local one, which is 20 mile away

**Val:** Hi Charles. How does your fatigue affect you?

**Charles:** I do all my exercises, etc but find that it leaves me exhausted for looking after two young children. I know if I do not do them it will be harder but the balance is hard

**Val:** The endorphins released by exercise should give you a 'lift' to deal with your children. Is it possible to change the time you exercise so that you can have an undisturbed rest following?

**Sarah W-OT:** Exercise is beneficial. How often do you exercise? What do you do?

**Charles:** Oh I forgot to say, I am married to a physio and I think she finds having a husband who could be a patient hard. If endorphins give a lift, is it silly to do my exercises at night ?

**Sarah W-OT:** Have you tried exercising first thing in the morning? Is that practical for you and you routine?

**Val:** Charles, I guess it depends whether you have problems sleeping

**Charles:** Morning is OK, but I battle on with university work when I get free time

**Alison:** I have found that with exercise just doing it when you can and feel in the mood works for me. Until recently I used to use a trike - manual - to get about and it was great to have exercise with the normal routine.

**Val:** Are you an OU student? They are particularly flexible to special needs

**Alison:** Charles, have you found your university sympathetic to your needs?

**Charles:** No I'm a Glamorgan online student and a Welsh College of Horticulture one. They are both good. I am doing studies to try to give me another chance with MS. It is hard to know how much to push the exercise when without it I will not cope, but with it I am fatigued

**Sarah W-OT:** It is hard to get the balance right. Just try different combinations of rest and exercise to see what suits you best.

**Alison:** Does anyone else have helpful people around them who are always telling them to sit down etc when I want to keep active

**Jennifer:** Yes, my son is amazing at telling me to sit!!!

**Alison:** I have been trying to do a counselling course and getting large print handouts or any recognition that I get tired is like getting blood from a stone

**Gail - OT:** Hello everyone

**Val:** I believe that there are now government employees from whom you can get an assessment and if they say you need large print it will happen. They also provide money to make modifications to computers. Also enquire through the student services at the University

**Alison:** It is a sixth form college. I get great support from Access to Work - brilliant scheme but this college just has problems with DDA part 4!

**Gail - OT:** Alison - what sort of problems do you mean?

**Alison:** Well, the managers understand it but the tutors seem to think it is asking a lot to blow things up. I was told it was too much trouble!

**Gail - OT:** Ouch!

**Alison:** Charles, do keep going. And if you can get a job, the Access to Work programme is brilliant. And if you apply, when you get a job it is free to the employer

**Val:** The unhelpful tutor could probably be taken to task over DDA

**Gail - OT:** It sounds like there is a communication problem between the managers and the tutors

**Alison:** I know. I have written to the authorities and suggested more training is needed and also help to promote services to students

**Gail - OT:** You said it was a sixth form college. Have you tried linking up with one of the other colleges to find out what they have done and see if they can offer you support in getting things changed?

**Alison:** The trouble is that as I had my licence taken away due to MS eyesight problems. It is the only one I can get to. But I will win the battle in the end

**Val:** The Open University wrote a booklet for OU tutors explaining exactly what they should and should not do. You could probably get a copy from your local OU regional office

**Alison:** thanks will make contact

**Gail - OT:** That sounds like a good idea. Hopefully it will enlighten them

**Alison:** How do you others find this hot weather?

**Jennifer:** It makes me tired

**Charles:** Having been beyond cold for five months, I am loving it

**Val:** I find the hot weather better and would like to overwinter in the sun but humidity is sapping

**Charles:** How nice to hear of another person with MS who wants heat. I thought I was weird

**Sarah W-OT:** That's interesting to hear, others today have said how the cold effects them more

**Gail - OT:** I think like Val says humidity is a problem - it somehow makes heat hotter

**Val:** Have you heard of the hot bath test that they used to use to diagnose MS?

**Gail - OT:** The hot bath test sounds humiliating. It must be horrible to be so vulnerable with strangers

**Jennifer:** Did your children (if applicable) cope well with diagnostic news?

**Charles:** My children were two and four. They now accept my wobbling and are good friends with therapists, but wonder why the doctors do not just fix me. And yes they laugh when I wobble from a hot bath, but I try to as well

**Val:** Some people have to rest for half an hour after a bath

**Gail - OT:** I've heard people have problems when a swimming pool has been overheated

**Alison:** My kids found it hard but I was told not to drive on the same day and it had a huge effect on my life

**Charles:** No, I can't drive either and yes it has big impact. But we are still friends and I have learnt to accept help.

**Gail - OT:** How did you tell your children?

**Charles:** I did not tell them other than to explain why I struggle to walk and I am tired a lot

**Jennifer:** Well, I rounded them up, then first explained that I am not going to DIE!!! Then that mummy gets tired and wobbly. One of my sons calls me his wobbly mummy.

**Gail - OT:** It seems really difficult to know how to pitch the information. MS isn't simple!

**Jennifer:** Tell me about it!!

**Charles:** I have found all children more understanding than adults and have learnt to laugh at the silliness of it all

**Alison:** I was told by the eye hospital in a half term appointment. I had my seven year old with me as she was off school and she said "what is the MS" as I burst into tears

**Sarah W-OT:** The books mentioned earlier have been useful for helping children understand MS

**Gail - OT:** Charles, I think younger children can have less prejudice than adults, but can find it harder to understand what it is

**Alison:** As a single mum, mine have seen every step of the way since then. The books were a great help but one is open and the other clams up and is angry. The worst thing is going into hospital and trying to get someone to oversee them.

**Gail - OT:** Locally our carers association have set up a scheme for children and teenagers to have someone to talk to

**Alison:** Yes we have a good one here in Cambridge. My daughter is making contact but my 15 year old son won't touch it

**Val:** I think boys find it harder to talk about their feelings

**Gail - OT:** I think it can be harder for boys as they don't have the same communication with friends as girls at that age

**Alison:** I think that boys in mid teens are struggling so hard anyway, especially with no Dad. Luckily mine has good and supportive friends

**Sarah W-OT:** That's innovative. Don't think we have anything like that here in Birmingham

**Charles:** Can you understand it? I think it is too easy to worry everyone and not get on with life, but that is where tiredness sneaks in

**Jennifer:** I am lucky in that my husband is very supportive

**Alison:** You can ask your local CVS ([www.csv.org.uk](http://www.csv.org.uk)) or DIAL ([www.dialuk.org.uk](http://www.dialuk.org.uk)) if there are young carers clubs near you

**Sarah W-OT:** Thanks Alison. I will look into it. It's been an interesting afternoon. Bye all.

**Simon - MS Trust:** Thanks Sarah for all your help

**Charles:** I think it may be harder when a mum has it as kids always go to her when young, boy or girl

**Gail - OT:** I think we all see our parents as permanent and it's hard when there's something wrong at any age

**Charles:** I am going now as I am freezing and I need the sun. It has been good, even if the only answer is there is no one answer

**Simon - MS Trust:** Thanks for your input Charles - enjoy the sun

**Jennifer:** Any top tips with dealing with fatigue?

**Simon - MS Trust:** The MS Trust publishes a book called Tips For Living With MS, which includes a section on fatigue. Either email me your postal address to [info@mstrust.org.uk](mailto:info@mstrust.org.uk) or you can download it from the publications list at [www.mstrust.org.uk/publications](http://www.mstrust.org.uk/publications)

**Simon - MS Trust:** A question sent in previously by Marcus: "I have MS. My carer (and some friends) accept this. I do experience fatigue and it is such that there is no argument when this happens. My carer (and some friends) know that fatigue is a condition associated with ms. What is a good method of communicating the condition to others who do not have ms and (sometimes) wrongly interpret the fatigue as laziness or as an imaginary condition that is being used as a false excuse. I accept that the fatigue element of ms is, in itself, a disability. How do I persuade others that it is not a choice and that I have no control over it?"

**Val:** Perhaps by showing them a copy of the factsheets from MS Trust and MS Society-so it is official!!!

**Gail - OT:** I've certainly come across family members who have thought it was laziness, I did some joint sessions explaining fatigue. I think fatigue is difficult to understand if you experience it - which makes explaining it harder. It's not as though there is anything for people to grasp - it's inside you

**Val:** If I say I am fatigued, my husband can always find something he is suffering from. I think I find people at work less sympathetic than family and friends

**Gail - OT:** I think it can be very variable as to who is sympathetic or not and sometimes people can be too sympathetic and smothering

**Jennifer:** It would be easier if you were wearing a plaster cast

**Gail - OT:** Exactly

**Val:** I wonder whether anyone with MS has taken any of the anti-fatigue drugs?

**Jennifer:** I haven't. Do they work?

**Gail - OT:** In the NICE guidelines they weren't really recommended as a first line of treatment as they only work on 40%. I think that drugs have to be seen as part of a possible solution not the only answer. Has anyone found something that is particularly good for helping manage their fatigue?

**Val:** Only pre-planning and only doing one major task each day

**Jennifer:** Like the hoovering

**Gail - OT:** When the physios said that hoovering couldn't be called exercise, my husband said they obviously hadn't seen me!

**Jennifer:** I find walking my dogs good exercise and good for my mojo

**Gail - OT:** Strangely exercise is good for fatigue

**Chet:** I find swimming helps me

**Jennifer:** Swimming is good

**Alison:** Has anyone tried yoga?

**Simon - MS Trust:** A study in the mid 90s found that not only was gentle aerobic exercise good for improving the response to fatigue and building strength but it also led to improved mood

**Gail - OT:** Our local MS Therapy Centre runs yoga classes. I think yoga is good because it's not a competitive thing, so you shouldn't overdo it

**Val:** Also yoga, in the same way as Pilates, provides some of the stretching which is good about exercise

**Gail - OT:** Yoga has controlled breathing and improving posture as part of it, so by improving posture and intake of oxygen you can feel better

**Chet:** So how would you define fatigue? For me, I feel that fatigue is feeling tired and wanting to fall asleep. Today, I fell asleep for two hours during the afternoon

**Gail - OT:** Fatigue is often "defined" as a feeling of tiredness that is out of proportion to what you might have done, and doesn't necessarily improve with rest

**Val:** In an article I read it said MS related fatigue was like living with a time consuming and all absorbing phenomenon. Would you agree?

**Gail - OT:** I think that's quite good - it sums up the effort you have to put into planning etc. But hopefully some things can become routine allowing fatigue to be something you keep at the back of your mind

**Chet:** Would medication help?

**Gail - OT:** There is some medication but it only works for about 4 out of 10 people with MS. Have you spoken to an occupational therapist about your fatigue and about strategies that could help? Also some medication that you might take for something else can make you feel tired

**Chet:** No, not spoken to anyone about it. Never really thought of it as a problem

**Alison:** I believe that we all develop strategies, both consciously and unconsciously. But it is so hard to accept the restrictions that increasing fatigue and disability bring

**Val:** A study at the MS Centre in Colorado suggested that modafinil and amantadine are quite widely used, but is it the same in the UK?

**Gail - OT:** I think we in UK tend to rely less on drugs than US in managing problems

**Chet:** I'm taking baclofen, which says it causes drowsiness. Would modafinil or amantadine be available to me in the UK?

**Simon - MS Trust:** Both amantadine and modafinil are licensed for use with MS in the UK

**Val:** Amantadine is recommended in the NICE guidelines. Modafinil was not licensed until after NICE.

**Gail - OT:** But not as a first or only line of treatment

**Chet:** I always have a baclofen tablet at 2pm and always seem to start feeling tired after that

**Gail - OT:** The baclofen might be making your fatigue worse. It's hard to get the balance between solving one problem and creating another. Do you try and fit lots of activity into the mornings before you fall asleep in the afternoon?

**Chet:** I work from home behind a computer from 8 -12 in the mornings. I don't have many commitments - all housework and cooking is done for me

**Alison:** I take Baclofen but take it three times a day and so take the second dose immediately I get in from work, which really helps with the tiredness.

**Gail - OT:** Concentrating hard for four hours will have an effect. Mental effort is as fatiguing as physical

**Simon - MS Trust:** Anna emailed in a question - she asks about the use of vitamin B12 for fatigue. Has anyone tried this?

**Chet:** I'd like to try the medications. If they work for me, would they get rid of tiredness?

**Gail - OT:** I think they reduce tiredness rather than get rid of it entirely. You probably could do with looking at what other strategies would help alongside

**Val:** In the Colorado study, about 40% of people thought that B12 was helpful. I had it weekly over three weeks but found no improvement.

**Chet:** What else could I do to reduce tiredness?

**Gail - OT:** Do you have a break while you are working, even if only to have a stretch and change position?

**annhas4hw:** Chet, have you tried serious exercise? It has helped me enormously with my fatigue.

**Gail - OT:** Was it you who said they swam? If so how often do you go?

**Chet:** I've just started swimming twice a week recently, and always stopping for a break during work

**Gail - OT:** Do you sleep OK?

**Chet:** I only sleep about six hours a night, then about two hours mid afternoon. I can never get to sleep early after being sleep for two hours in the afternoon

**Gail - OT:** Have you thought of trying relaxation or meditation? Some people find that helps with fatigue. As you take baclofen do you have problems with spasm at night? On another tack - is the chair and desk you sit at to work comfortable?

**Chet:** I have just bought a height adjustable chair that is more comfortable and always make an effort to sit straight. At night, it seems all my problems

disappear. My walking seems to be virtually normal - I can even walk up the stairs without holding onto the sides holding plates. I always feel better naturally at night. Does anyone else find this?

**Gail - OT:** Do you have to type a lot? It might be worth thinking about how you have your monitor etc set up.

**Val:** I think people who take no break actually feel worse at night

**Gail - OT:** I think some people find a sort of rhythm over the course of the day, feeling tired in the afternoon and getting a second wind in the afternoon is common

**Chet:** Not much typing at all - but lots of thinking and it gets stressful at times

**Gail - OT:** It might be a good idea to try relaxation or meditation to help manage the stress. Stress can make fatigue worse

**Chet:** Who can help with relaxation and meditation?

**Gail - OT:** If you try relaxation, don't do the progressive muscle relaxation. A physio I know thinks that can be counter-productive. You can try a tape, or if you have contact with a rehab service or Therapy Centre, they may be able to help you learn how to do it

**Simon - MS Trust:** The MS Therapy Centres offer a range of therapies that might fit with relaxation - massage, aromatherapy, reflexology, etc

**Chet:** OK. I've been meaning to go to the Therapy Centre ever since I passed my driving test, so I'll go tomorrow

**Gail - OT:** Generally you have to practice to get the hang of it, it's not a quick fix! Does fatigue stop you doing things socially?

**Chet:** No, not really. I miss a few things socially like shopping but I don't think I could manage that because of the long walk

**Gail - OT:** Have you thought of trying using a scheme like Shopmobility, which hires out scooters in shopping centres. Or would you feel uncomfortable about it?

**Chet:** I'd feel uncomfortable about using scooters. I don't even want to use a walking stick

**annhas4hw:** Shopmobility is brilliant! It helped me a lot and I enjoyed scooting around on their machines. It was embarrassing at first, being on a scooter, but I soon got over that. It was so enjoyable as well!

**Val:** You will find that children are very jealous of the scooter. I had one at the Millennium Dome and it was great

**annhas4hw:** Yes, the young ones often want "a go" on mine!

**Chet:** My main mode of transport is my car along with my badge that I can park virtually anywhere, and I'm not really the biggest shopping fan!

**Gail - OT:** It might be good to weigh up the pros and cons of using equipment - but it's a personal decision

**Chet:** Being quite young, I couldn't handle people staring at me on a scooter

**Gail - OT:** What about going out with friends and family?

**Chet:** I've got four weddings coming up in the next few months. As long as there is not much walking and I've had a long sleep I can handle things with small amounts of walking, but I end up sitting around most of the day

**Gail - OT:** There's always so much standing around at weddings. What about a sort of shooting stick that you can perch on?

**annhas4hw:** Chet, people don't stare at scooters! They are so commonplace these days!

**Chet:** Thank you all for your help and advice, it was great talking to you all. I have to go now.

**Simon - MS Trust:** Thanks for your input Chet

**Val:** Ann, how is your fatigue level at the moment?

**annhas4hw:** My fatigue level is MUCH better than it used to be!

**Gail - OT:** What's your secret formula?

**Val:** So what is your secret?

**annhas4hw:** We joined the local gym a few years back! No secret, just exercise!

**Simon - MS Trust:** Did you take this up after you were diagnosed or have you always done that sort of thing?

**annhas4hw:** I've been diagnosed over 25 years. Not into sports or exercise at all previously.

**Val:** I think that, in a way, I am fitter now than before diagnosis as I had worn myself out trying to keep up with those without MS. The diagnosis also meant that I had to rethink my life and exercise and a lower fat diet has helped

**Gail - OT:** I think that there's a lot that can be done just by looking after yourself

**Val:** There is also the Expert Patient Programme being run now by most Primary Care Trusts. The course is for anyone with a chronic condition. It is interesting to find that fatigue is common to all chronic diseases. It gives it a bit more legitimacy.

**Liz:** Hello. I have very weak muscles, including those responsible for breathing apparently. Everything requires an extreme effort.

**Val:** Are you able to have one-to-one physio to help your muscles?

**Gail - OT:** Do you do any exercises to develop your muscles or is that too difficult for you?

**Liz:** I do exercises regularly, but they seem to make matters worse, especially around the knees.

**Gail - OT:** The MS Trust has just published a book of exercises

**Simon - MS Trust:** Yes, it was written by physio. It can be downloaded or ordered from the publication list at [www.mstrust.org.uk/publications](http://www.mstrust.org.uk/publications)

**Val:** Might yoga be a better alternative

**Gail - OT:** Do you get hot when you exercise? What sort of exercise do you do?

**Liz:** Not especially, and I always have a cold bath afterwards.

**Gail - OT:** Sometimes if you do lots of repetitious exercises it can "short circuit" your muscles into being fatigued

**Liz:** I find that only one or two movements of the knees sets off problems in the nerves. How can I avoid that?

**Gail - OT:** Do you see a physio?

**Liz:** Yes, very occasionally.

**Gail - OT:** It might be helpful to get their advice. Have you tried swimming? It might make a difference if you are not weight bearing

**Liz:** I'm afraid swimming makes me ill.

**Anne Marie:** I have been diagnosed since 1998. I have problems with fatigue & balance

**Val:** Anne I was also diagnosed in 1998, although the diagnosis took 12 months - very fatiguing

**Gail - OT:** I think the whole stress of diagnosis takes a big toll on you

**Val:** I also have problems of fatigue and balance, but the fatigue is better since I learnt to say NO

**Anne Marie:** I now cannot drive until I get the OK from the neurologist. The appointment still hasn't even come through yet

**Liz:** Is it a bad thing to sleep too much? Should I struggle to get up early and stay awake?

**Val:** I find that ten hours sleep at night is what I now need

**Liz:** Yes I get at least ten hours, but wondered it perhaps I should be fighting it more. How about caffeine?

**Gail - OT:** Too much caffeine isn't good for you! It's an artificial stimulant that you will have to come down from

**Val:** I think it is very important not to fight fatigue. Rather keep a diary of when it happens and start resting before then

**Liz:** I don't take any .I suspect I'm in the minority.

**Simon - MS Trust:** Liz, does the amount you sleep interfere with your day or do you just feel guilty that you sleep more than you used to?

**Liz:** Both.

**Simon - MS Trust:** Have you seen anyone about this? Fatigue management can involve OTs, physios and also there are drugs that can complement this

**Liz:** How can I eat without feeling like collapsing?

**Gill:** Hello I have been diagnosed as relapsing/remitting a year ago. I am on Avonex but still get really really tired despite having packed up work. Is this to be expected

**Gail - OT:** Eating can make you heat up, so perhaps little and often may help. Some of the drugs like Avonex can have the side effect of tiredness

**Darren:** Hi

**Gail - OT:** Do you have anything to say about fatigue?

**Darren:** I was wondering how people deal with tiredness. I have a busy full time job that can get me down

**Gail - OT:** What does your job involve?

**Val:** I may not be the best person to answer that as I opted for medical retirement and part time work

**Darren:** I work in the motor trade and I can't really relax during the day because of a constant flow of customers

**Gail - OT:** As we've been talking there's different things you can try but they need to fit in with what you do. Are you on your feet a lot?

**Val:** I find that I can cope with part time work by pre-planning and making only one trip around my office rather than several

**Gail - OT:** Do you work alone?

**Darren:** I get to sit down a lot but I find the mental strain can be really overpowering

**Gail - OT:** Do you get the chance of a lunch break?

**Darren:** Not really.

**Gail - OT:** If you get the chance of a break you could try having a change of scene, getting some fresh air, or learning a relaxation technique

**Liz:** Sitting for long periods can be almost as fatiguing as moving. It's very difficult to start to move again.

**Darren:** As I get paid by selling cars, if I miss people, I don't earn and I have all the normal bills to pay

**Gail - OT:** Some relaxation techniques can be done during a quick break in the loo for a couple of minutes, they don't have to be long and involved

**Darren:** Like what?

**Gail - OT:** Concentrating on deep breathing, very slowly. It might help you feel better. When you go home are you too tired to do anything enjoyable? And do you "catch up" by sleeping over the weekend?

**Darren:** What drugs are there that people take?

**Gail - OT:** Amantadine and modafinil - nothing too exciting!

**Liz:** What are people's experiences of drugs like amantadine?

**Val:** I have not tried amantadine, but a side effect for some is that it causes difficulty sleeping. Modafinil has only become licensed for MS recently and so no anecdotes

**Simon - MS Trust:** The recommendation with amantadine is that it is not taken after about 2pm so that it doesn't interfere with normal sleeping patterns

**Darren:** I try to sleep at the weekend but that's only if I'm not working. I have to work six days a week

**Gail - OT:** That's really hard. It sounds as if all you do is work and sleep, Darren

**Darren:** Pretty much. Boring huh?

**Gail - OT:** Well not very satisfying. You must get frustrated

**Darren:** I try to go out but by midnight I'm shattered

**Gail - OT:** Some of us have always been shattered by 11!!

**Darren:** I guess I get off lightly then

**Gail - OT:** Have you been diagnosed very long?

**Darren:** About three or four years. It started six years ago though

**Gail - OT:** I think it's more to do with what you're used to. Could you afford to reduce your hours to say five days per week?

**Darren:** The job doesn't allow it unfortunately. I'd have to leave and find something else

**Gail - OT:** Have you always worked selling cars?

**Darren:** I used to work in a shop but it was so mundane. I like to talk to people

**Gail - OT:** When you say you would have to leave is that because you don't think your boss would help you?

**Darren:** No, it's just the way the motor industry is. It's a kind of all or nothing type of business. But it can pay well which is what keeps me there

**Gail - OT:** Have you tried talking to anyone about how tired you get?

**Darren:** My boss knows, but I can't really ask for time off all the time. I'm one of the managers you see

**Gail - OT:** I think it would be helpful if you could talk through some different options with someone independent. It's difficult when you are a manager, as you want to be in control

**Gail - OT:** Have you had any contact with an occupational therapist?

**Darren:** No. Do you think it's worth it? What do they talk about?

**Gail - OT:** I'm one! They can help you think about how you can use your energy and perhaps think about what you could do at work

**Darren:** Maybe its worth having a proper chat. How do I go about it?

**Gail - OT:** Your GP should be able to refer you to an OT - preferably one who works in neurology

**Darren:** Is it worth trying to get modafinil?

**Simon - MS Trust:** Managing fatigue can involve physios, OTs and doctors as well as being aware of your own limits and adapting your life to this.

**Gail - OT:** As Simon says, it requires a team effort. Drugs alone are not the answer, and they only work for 40% of people

**Darren:** Oh, I see. Well thanks anyway. I'll contact my GP and see how it goes

**Simon - MS Trust:** It's 7 o'clock so we will have to close the room. Thanks to all who have taken part and to Val, Gail, Sarah B and Sarah W for acting as experts