



Wellness

**approaches to general health
and well-being**

Chatroom

3 December 2002

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Wellness

3 December 2002 – 10am to 7pm

The experts:

- **Megan Burgess**
MS specialist nurse (10am – 3.30pm)
- **Gail Townsend**
Occupational therapist (11am – 3pm)
- **Jenny Craig**
Physiotherapist (3pm – 7pm)
- **Michelle Ennis**
Occupational therapist (3pm – 7pm)

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<Simon, MS Trust> Welcome to the MS Trust chatroom on wellness

<Megan, MS Nurse> Hello Karen

<Karen> I was diagnosed with relapsing/remitting MS in August and am seeing an MS nurse in March next year and I am wondering what information he will be able to give me

<Megan, MS Nurse> I'm glad you have access to an MS nurse. We always try to answer any questions you may have about your MS and it's effect. It is often a good idea to jot down any questions you have before you see him as I often find people forget everything they wanted to say once they get to see me. Many MS nurses also run courses for people newly or recently diagnosed with MS. These usually cover all sorts of things including symptom management, coping with fatigue etc., and generally how to look after yourself and keep yourself as well as possible.

<Simon, MS Trust> Hello Geraldine. Do you have a question for Megan?

<Geraldine> Hi. I joined in one of the MS Trust's earlier chat rooms so I wanted to see what was being said in this one.

<Megan, MS Nurse> OK, hope you find it interesting - do join in if you want to.

<Geraldine> When I was diagnosed, my neurologist told me about eating low fat food - skimmed milk etc. Could I just ask the MS nurse (hello Megan!) whether that's right?

<Megan, MS Nurse> Yes - we usually advise people to cut down on saturated fats - things like high fat dairy products, red meat etc. but to maintain or even increase your intake of poly unsaturated fats - things like sunflower oil

<Geraldine> Is that as easy as using sunflower instead of virgin? And what about fish oils?

<Megan, MS Nurse> Yes - or you can use a combination of both - lots of people use a sunflower spread. Don't deprive yourself of something you really enjoy - olive oil will be OK too. Fish oils and evening primrose oil or starflower oil are also OK and some people prefer to take these as supplements.

<Geraldine> Thank you Megan. That's really helpful. I think I'll have a look at what's available at the health food shop by way of capsules.

<Simon, MS Trust> Charles, do you have a question for Megan?

<Charles> I am off to the consultant in 20 minutes. Is there a question I should ask when steroids are hopeless? I have been diagnosed since August although I have had symptoms for 10+ years. I do not know yet what type of MS I have.

<Megan, MS Nurse> Hi Charles. Even if steroids are no longer helpful, there is usually something that can be done to help in terms of symptom management or in terms of making the symptoms a little easier to live with. Perhaps you could discuss this aspect of things with your consultant.

<Charles> I have only had steroids once with no effect. But physio and prisms in my glasses have helped. But I want a bit more control of me. Is this crazy optimism?

<Megan, MS Nurse> It is often difficult to say what type of MS someone has, particularly in the first few months/year or so after diagnosis. The different types all sound very clear cut when you read about them but aren't like that in reality.

<Charles> So, does this rule things in or out?

<Megan, MS Nurse> Sorry Charles, I'm not sure what you are referring to?

<Charles> I feel that I have so few times to see the consultant I want to get the best from it, but I am not sure of interferons etc

<Megan, MS Nurse> The best thing to do if you have time is to write out a list of the topics you want to discuss with the consultant eg interferons, type of MS, further management options etc. If you have access to an MS nurse locally, they may also be able to help.

<Charles> Sorry I have to go now, but thanks.

<Megan, MS Nurse> Hope it goes well.

<Simon, MS Trust> Hello Alico. Do you have questions for Megan or Gail?

<Alico> Yeah, should taking dothiepin really send me crazy!! I started it on Friday and can't stop shaking and am very dizzy

<Megan, MS Nurse> Hi Alico - No dothiepin shouldn't make you feel crazy! It maybe that there are other options you could discuss with your doctor. What dose are you taking - usual the starting dose is about 10mg- 25mg.

<Alico> I was taking paroxetine but wasn't doing much and I was having trouble sleeping, so my neuro suggested this. I only started on Friday on 25mg. I have strange thumping in my chest too!!

<Megan, MS Nurse> It may be that you need to reduce the dose down to 10mg or to try another medication that has similar benefit. You should probably discuss it with your GP asap.

<Alico> Could these be withdrawal effects of paroxetine?? I have an appointment arranged for Thursday.

<Megan, MS Nurse> I'm not sure whether this is withdrawal of paroxetine, although I think it is unlikely. To help you sleep, another option to dothiepin that many people with MS take for various reasons is amitriptyline. See how you feel as to whether you want to stay on the dothiepin until you see your GP on Thursday or have a break until then

<Alico> I just feel so low and needed someone to talk to, hope I don't bring everyone else down with me!!

<Megan, MS Nurse> Sorry you are feeling so low. Medications do help of course but you may find it helpful to talk to someone as well. Do you have access to an MS nurse or a counsellor? If not, maybe your GP can arrange this.

<Gail Townsend OT> Alico, if you're feeling low it's better to try and get things off your chest rather than bottling things up, because you're worried about other people. If you don't have access to an MS nurse your GP may be able to help.

<Alico> I do have an MS nurse but its just trying to get there with my little girl too! I live away from family and friends.

<Gail Townsend OT> Have you asked the nurse if she could see you at home?

<Megan, MS Nurse> I appreciate travel is difficult, especially with children! Either the nurse could see you at home or, at the very least, she should be available on the end of a phone to talk you through things

<Alico> I will do - thanks for the help and for listening.

<Megan, MS Nurse> No problem - hope you get sorted.

<Jay> There's nothing worse than side-effects from drugs. It makes you feel a wimp for not putting up with them and upset because you're not getting help from them.

<Chloe> I get tired soooo quickly. Not sure who that would be for, sorry.

<Gail Townsend OT> Chloe, are you wanting to know more about how to cope with fatigue? Do you want to tell me a bit more about your tiredness?

<Chloe> It's just seems so unpredictable. I'm never sure if I'll be able to do what I want the next day or not.

<Gail Townsend OT> Are you working? Do you have a busy home / family to organise?

<Chloe> I've got two kids. But not working anymore.

<Gail Townsend OT> Chloe, looking after children and running a home can be very tiring. Particularly if you are helping your children do all the things they want to do, do you have any family or friends nearby for support?

<Chloe> My mum lives nearby but she works full time. It's not that I can't cope because I can, it's just the unpredictability of the tiredness makes planning really difficult.

<Gail Townsend OT> Are you finding that it's difficult to sleep? Do you tend to be on the go all day and then flake out, or do you squash everything into a good day?

<Jay> Anyone got any helpful ideas for severe leg pains?

<Megan, MS Nurse> Hi Jay, do you know what is causing your pain? Is it to do with spasms etc. or are your legs just really painful?

<Jay> Not spasms, just pain and burning sensations.

<Megan, MS Nurse> This type of pain is unfortunately fairly common in MS. The sort of medications that we use to treat it are either anti-epileptics (eg carbamazepine, Neurontin) or anti-depressants, such as amitriptyline, as these drugs get through to the central nervous system which is the cause of the problem

<Jay> I've tried all those over the years. You have to take them for a few weeks, side effects very unpleasant. I'd like something to take when I've got the pain, which fortunately is only sometimes. I have found using tight crepe bandage round my legs helps!

<Megan, MS Nurse> Sorry you have tried things with no luck - I do have some people who just take Tegretol when they get the pain - with some success. The other option is to request a referral to a pain management team

<Chris> Megan, I'm taking Tegretol to help burning pain in my feet. It works but could my increased tiredness be a side effect? I was already taking amantadine (about 12 months) to deal with fatigue before the Tegretol.

<Megan, MS Nurse> Hi Chris. Unfortunately Tegretol can cause increased tiredness - sometimes this wears off after a while but sometimes not. It is often a matter of finding the balance between fatigue levels and controlling the pain. If it gets very bad you maybe need to try something different

<Gus> Hello all, I'm Gus. Unlike a lot of MS sufferers, I am mobile and don't get dramatic relapses. I do feel generally unwell a lot of the time - half the time in winter - achy, fluey feelings with disturbing head sensations often accompanied by a mild cold. I also get a lot of fatigue. Are the "fluey" feelings known/common problems associated with MS? Since this occurs more in winter might it be related to poor immune system? If so, can anything be done to boost immune system? Sorry about multiple questions!

<Gail Townsend OT> Gus in the winter it's important to make sure you eat properly (5 fruit and veg) and try and get out in the fresh air as this can help clear your head

<Megan, MS Nurse> Flu like symptoms aren't really part of MS - have you talked to your GP about this - could it be anything to do with your sinuses??? I haven't really noted any trend for people with MS to be more vulnerable to coughs and colds etc.

<Gus> Thanks for advice. Yes I eat properly and get fresh air. My GP did wonder about sinuses but nothing resolved. Reference fatigue - like others I get this a lot and often without warning, quite unpredictable. Am I alone in that mine is not a sleepiness - in fact although I would like to sleep. Any thought, anyone? I often can't sleep when I'm "MS fatigued".

<Simon, MS Trust> hello Anne Marie. Do you have a question for either of our experts?

<Anne Marie> I am a newly diagnosed MS sufferer. I have found that I am affected by the cold which causes pain to increase can they recommend any measures I can take?

<Megan, MS Nurse> Hello Anne Marie. A lot of people with MS find the heat really difficult to cope with but, as you say, many also find the cold very difficult and it can cause increased problems with pain and stiffness. Apart from obvious measures like keeping yourself comfortably warm, there are medications you can take which may help with the pain. Do you think the pain is cramp like, due to stiffness, or is it more like a nerve pain?

<Jay> Re: fatigue, also heat. I find cooling very helpful. I have an old machine with cooling jacket and this is great. 30-40 minutes gives me a bit of extra energy and its great if the weather is warm though I now use all year round.

<Anne Marie> It is cramp in the left arm and leg - but nerve pain in the head

<Megan, MS Nurse> The treatment for these 2 types of pain will be different. You will probably find it helpful to see a physio for advice on the cramps etc. if you haven't already - plus sometimes a small dose of something like baclofen may help. The nerve pain in you head will need a different type of medication if you wanted to try anything for it although you may well find it settles down in time

<Simon, MS Trust> Anne Marie, we'll have a physio in the room later in the day (between 3pm and the close at 7) if you have the chance to be around then.

<Anne Marie> The physio room would be great. I will just read now as all topics/info is useful to me

<Gail Townsend OT> Gus, (and Chloe!) it might be worth trying to keep a diary over a couple of weeks because that can sometimes show up a pattern that isn't always obvious. It's important to remember that it's not just physical things that make you tired. Watching telly takes a surprising amount out of you - it's not classed as doing nothing.

<Megan, MS Nurse> Gus, fatigue in MS can be horrid. It is nothing like tiredness that everyone gets and often others find this difficult to understand. There is no easy answer, although pacing yourself - trying to find the fine line between pushing yourself and overdoing it (which you don't want to do) is both important and difficult - especially as you will find it changes day by day.

<Gus> Yes, Gail, I've kept a diary for over 20 years of MS! Never found a pattern. Sorry to be awkward!

<Gail Townsend OT> Chloe do you worry about asking for help?

<Jill> Hi Anne Marie. I find both the heat and cold difficult. During the winter I have to make sure that the central heating is on all day (!) Doing exercises helps to counter the stiffness and going out in the cold evenings can be awkward but better with help at hand . I try not to drive myself which helps as then I can have a drink - LOL

<Gail Townsend OT> Gus, I've certainly come across lots of people with MS who have difficulty sleeping, but it's a common problem in the general population too. What have you tried to help with sleep?

<Jay> Gus, I find sleep a problem if I'm MS fatigued.

<Gail Townsend OT> Gus to go back to the diary thing, have you tried noting how long you did each activity and how tired you felt afterwards? Plus adding in how you slept, or didn't?

<Gus> Valium helps but I don't want to take this too often/regularly. The worse the fatigue, the harder it is to sleep.

<Gail Townsend OT> Have you tried relaxation or the perhaps the use of aromatherapy oils?

<Chloe> Interesting that fatigue bothers Gus too. Hi Gus! I'm not worried about asking for help. I just know that a lot of young mums get tired (who wouldn't?!) and I don't know how much of it to put to the MS.

<Gail Townsend OT> Chloe, that is always the million dollar question! In some ways young mums with and without MS can fall into the same trap of trying to be superwoman

<Megan, MS Nurse> Chloe, it is often a matter of trying to prioritise the things that are important (and that doesn't include housework!) each day and pacing yourself

<Jay> Gus, I find camomile tea helps a bit, also relaxation techniques

<Megan, MS Nurse> Gus, re: sleeping - do you try and get yourself into a regular routine before bed? If you are OK in and out of a bath, this may help. Avoid stimulants such as coffee, tea etc. just before bed - and often stuff such as lavender oil may sometimes help. As you say, Jay, camomile tea is also good

<Jill> What we eat can make us tired too. It might be worth cutting down (not cutting out) on carbohydrates. I find that I need to eat regularly but feel tons better when I reduce the amounts of wheat that I eat for example.

<Gail Townsend OT> Some psychologists recommend that you develop a routine when you go to bed to help your body prepare, and they advise that you don't read or watch TV in bed as this is giving the message that you want to stay awake, and stimulating the brain

<Jill> Re: sleep. Occasionally it can be the bladder that affects sleep patterns. Managing that can help with sleep eg by drinking loads during the day but cutting down fluid intake in the evenings so that a full night's sleep can be enjoyed.

<Gus> Hello Chloe. Yes, fatigue is such a problem isn't it? I can't pace myself or plan because it's so unpredictable and can start very suddenly. Sometimes I can work quite physically, quite a lot, with no ill effect. I think this is very common.

<Gail Townsend OT> Chloe, delegation is also a good strategy. Remember you don't have to do everything, and I agree with Megan housework can wait. There are more important things, such as enjoying time with your children. Pacing and planning can seem unnatural. It's not a quick solution, and it can be frustrating to lose being spontaneous, but sometime by spacing things out you can make the dips last a shorter period of time

<Jay> Chloe, pacing is a bore but can help. I find when cooking if I organise it so that I can rest in between - eg when spuds are cooking - it does help.

<Gail Townsend OT> Chloe do you have access to an OT near you who can help you look at some of your issues around fatigue and help you come up with some solutions that will help you?

<Simon, MS Trust> Hello Chris, do you have a question for Megan or Gail?

<Chris> I take amantadine and have been told that it has anti viral properties. Is this so?

<Simon, MS Trust> Chris, Megan's checking the books

<Megan, MS Nurse> Hi Chris. Sorry, just looking that one up! You're right. It's not something I have come across before but MIMS [*Monthly Index of Medical Specialities - a drugs reference book*] does in fact list amantadine as a 'viral replicator inhibitor' - usually given in this context for just a few days. As I'm sure you know, we use it in MS to ease symptoms of fatigue

<Jill> Being "well" is such an individual thing. Any tips on how to measure up to our own needs/standards rather than comparing ourselves and what we can /can't do with others with MS or without it? I think the diary is a very helpful suggestion.

<Simon, MS Trust> A good point, Jill. Do you have any strategies for this?

<Gail Townsend OT> Jill, I think the best way you can measure your own wellness is against yourself. As MS isn't static though you need to look at different times at what makes you feel good, even in a bad patch

<Megan, MS Nurse> Hi Jill. I agree with Gail. MS is such an individual experience for everyone. Something we are coming to realise as health professional (rather belatedly!) is that most of the scores we use to measure peoples 'progress' with are related to outcomes that have little importance to the person with MS - who after all is what it is all about!

<Anne Marie> I first saw the MS nurse at the beginning of Nov. I have been keeping a diary since then. It is very useful when you think you are having a really bad day and you just look back to see that you have been worse

<Gail Townsend OT> Anne Marie, the other use of a diary would be to find out what went well and to see if you can duplicate that success

<Jill> Thanks for all the tips. When I have a "not so good day" I try to remember that yesterday was better. The best thing I ever did was realising that I couldn't do the housework without help. It didn't take too long to stop feeling guilty that someone else did it for me.

<Anne Marie> Gail, I do do that! It's just that this is all new to me!! And I know the importance of positive thinking!!

<Gail Townsend OT> Anne Marie, the human condition is to see our failures as somehow more important than our successes, and having MS can sometimes make that worse

<Jay> Megan do a lot of people get "weepy" when fatigued? I'm not feeling upset but I just sort of cry spontaneously.

<Megan, MS Nurse> Some people with MS find that they cry (or laugh) spontaneously for no real reason. This has the dreadful name of emotional incontinence, I'm afraid. It could be that this is the problem. Like many MS symptoms it will get worse when you are tired. Often a small dose of amitriptyline will solve the problem

<Chris> Megan, amongst friends at my MS branch many now seem to take Zanaflex instead of baclofen. What is the difference?

<Megan, MS Nurse> Hi Chris. Zanaflex is an alternative to baclofen - it does the same job but is supposed to cause less weakness. However it can make people more tired and as it has to be built up gradually while baclofen is weaned off gradually it can be difficult to get settled on initially. Like any drug - some people do well on it and others don't. Baclofen is usually tried first and if that doesn't work then Zanaflex can be tried

<Jill> Jill I didn't know baclofen had to be reduced gradually. I vary the dosage from day to day - is this a problem? I am mindful of the fact that my symptoms vary so my need for the drug will vary too.

<Megan, MS Nurse> Jill, you are OK to vary the dosage of baclofen within 10 mg or so each day. It is only if you are taking more than 30mg daily that you have to be careful when stopping as doses in excess of 30mg shouldn't be stopped suddenly

<Chris> Gail, I decided to go back to my PhI exercise in the lovely warm water. This has been excellent for my spastic leg and solid foot. The confidence of still being able to achieve something is amazing and I would recommend movement in warm water to anyone.

<Gail Townsend OT> Yes, lots of people find they can move more freely in water. The only note of caution is that it can be easy to overdo it as it seems so much more easy, so as always, and rather boringly, moderation is the key

<Jill> Chris, I too enjoy swimming and exercises in the pool. I feel exhausted physically afterwards but fully alive mentally!! It really is worth all the effort of getting in and out of the pool.

<Gail Townsend OT> Regular exercise can help with fatigue as you are improving your underlying fitness, and doing nothing ultimately can make you more tired

<Jay> I go to a gym for disabled and able people and do a bit on some of the machines. It makes me feel part of the world!

<Jill> Would that there were more mixed gyms for able-bodied and disabled people to use together.

<Jay> Would that there were more MS nurses to talk to. There are none in my area

<Gail Townsend OT> Jill, some areas are trying to develop better facilities for gyms etc. It might be worth finding out what your local council is doing

<Megan, MS Nurse> Jill/Jay, I'm not sure how widespread it is, but I know in some areas you can get a prescription from either physio or GP to attend a gym. And most gyms will cater for both disabled and able-bodied even if this isn't explicit

<Lucy> I swim twice a week - it keeps me fit. This morning I was too tired to face having to get undressed/dried/dressed, so I spent an hour on the toning tables at the gym. Relaxing and fun!

<Simon, MS Trust> Whereabouts are you Jay?

<Jay> I'm in Herts.

<David> I also have 'dark' days where I feel fatigue and low - but the following day may change everything. I seem particularly sensitive to temperature. A warm day in summer makes me want to stay in bed and sleep and the sort of winter's day like today where people think it a good thing to turn their heating up is an anathema to me.

<Gail Townsend OT> David, heat does tend to increase fatigue. In the summer using a fan and having cold drinks to keep your temperature down can help

<David> I agree totally about using fans, but some of my relatives may look at me a little askance if I sit by a fan!

<Gail Townsend OT> David, but if it helps you control your symptoms, they can get used to it - unless you live with people who feel the cold!

<Jill> Here's another question! There are many similarities between chronic fatigue syndrome and MS - is it helpful to look at both conditions together or not?

<Gail Townsend OT> Jill, while there are some similarities between chronic fatigue and MS, there are probably more differences. While people with chronic fatigue do get pain and weakness, they don't tend to get some of the other problems which often complicate things for people with MS

<Megan, MS Nurse> I'm not aware of very much written about the relationship between MS and chronic fatigue but it is certainly worth looking at strategies that help with CFS as they may well be useful in MS

<rose> I had a baclofen pump fitted in July and I had a further operation 3 weeks ago because it went wrong. What is the latest medical opinion on these pumps?

<Megan, MS Nurse> Hi Rose, sorry things went wrong for you. These pumps can still be very useful for many people, but unfortunately like anything else they don't suit everyone

<Chris> Jill, my last message about physio pool was all messy, don't know what happened, I'm new to computers! But I couldn't agree more. My friends thought I was mad, as I couldn't stop saying how much better I felt after 20 minutes in the pool!

<Jay> Going now, back later. Thanks all. Even if you learn nothing new, it is very helpful to "be" with other MS people and professionals - it gives a bit of reinforcement!

<Jill> Hasn't Jay expressed that well. I'm off to do battle with my local council - LOL. Bye all.

<Simon, MS Trust> Good luck Jill!

<Megan, MS Nurse> Hello Terl

<Terl> Ah, an MS nurse they are like hens teeth lol

<Megan, MS Nurse> Sorry you have no one local. Our numbers are growing, although slowly. There were only about 5 MS nurses when I started in post. I believe there are now about 140 of us

<Simon, MS Trust> Jay, you're right about the lack of MS nurse coverage in Herts. As Megan says, coverage has improved greatly in recent years but there is still some distance to cover

<Gail Townsend OT> Jay, do you have an MS therapy centre nearby? **<Simon, MS Trust>** There is one in Harrow

<Jay> Yes, within reasonable distance. I used to go but not too fond of driving far if I don't have to.

<Gail Townsend OT> Perhaps there is someone you could link up with who might be happy to drive, or is there a local transport scheme you could use?

<Simon, MS Trust> There's also a good therapy centre in Bedford, if train travel is less daunting than driving

<Gail Townsend OT> The MS Therapy centre in Bedford also have an MS nurse

<Jay> Thanks. Bedford a bit far and I can't do trains.

<Terl> I'm from Lincolnshire safest place to live so you can't 'catch' MS. The NHS thinks so as no MS nurses or neurologists Lol. Oh I know I wind up the PSG etc all the time lol. Trouble is that MS nurses should not have to be funded by charity in the first place

<Megan, MS Nurse> You are quite right - funding of MS nurses is still ad hoc at best. I am cautiously optimistic that the NHS in general and PCTs in particular are becoming more sold on the idea. I think the DoH risk-sharing scheme and the NICE guidelines etc. due to be published next year will help

<Terl> I have 2 PCTs in my district and although they will give lip service to specific nurse support they are reluctant to fund!! I actually asked questions about funding for specific medications (beta interferon inferred) and asked if they got additional funding and if not what were they going to cut or do to provide it or arthritis type drugs. Silence was the answer

<Gail Townsend OT> Do you have a local Neurological Alliance, as that may be one way of trying to influence change in a more formal way. Local councils are also being required to develop strategies for people with physical disabilities, which should involve health too. It might be worth investigating what's going on

<Terl> I am Chairman of Local District Council, Gail, and its uphill work to try to change the way they work and get funding allocated

<Megan, MS Nurse> It is often a matter of continued lobbying, which I am sure you are involved in. Funding of interferons and Copaxone is now mandatory although unfortunately quite a few areas are still not up and running with this due to lack of infrastructure (read funding). I know that all neurological centres listed as prescribing centres for interferons were given some monies towards MS nursing as they can't be given without MS nurse support

<Terl> No we don't have a Neurological Alliance. I would think you would need a neurologist to be central for that

<Gail Townsend OT> The Neurological Alliance is made up of voluntary bodies like the MS Trust, MS Society, Parkinson's Disease Society etc. It's a way of what can seem small organisations getting together to pool their resources. It shouldn't need a neurologist.

<Terl>, Interesting. Don't have an effective MS Society branch locally, yet in the town there are 60 folk with MS on doctors' books and there are four similar towns I can group in the district

<Gail Townsend OT> It might be worth contacting your regional group or co-ordinator for the MS Society. In Thames Valley, where I work, our regional chairman has been instrumental in developing a Neurological Alliance in Buckinghamshire

<Simon, MS Trust> Hello John. Do you have a question or thoughts to add to the discussion?

<John> It's probably already been asked, but how can I, with my MS, improve my general health and well-being?

<Gail Townsend OT> We can all do things to improve our health. As a nation we are not very good at healthy eating and exercise. Is there something in particular you would like to change to feel more "healthy"

<Megan, MS Nurse> John, the \$64 million dollar question! It would be impossible to cover everything here but looking after yourself generally - the sort of advice that we should all follow - taking appropriate exercise, learning to pace yourself, eating healthily, sleeping well, doing things you enjoy will all help

<John> I already eat well and reasonably carefully. Exercise seems to take too much effort for too little gain!

<Gail Townsend OT> Even gentle exercise can help. Sometimes by doing less it can increase the feelings of fatigue. Making sure you get enough fluids is also important as we often don't drink enough and are a bit dehydrated

<David> Megan has the right idea. Eating healthily does not in my opinion make me better but I can get worse for a couple of days if I don't eat healthily

<Tim> Hello. I have a question about heat. I understand it can bring on more symptoms. I am recently diagnosed. I am looking to return to a hot climate where I normally work, max 32 Centigrade. Is it wise?

<Gail Townsend OT> Tim, will you have air-conditioning or will you be outside most of the time?

<Tim> Air conditioning is too expensive. I work in an office. I have fans only.

<Gail Townsend OT> Do you have to dress formally in a suit and tie, which is often hotter, and can you take breaks regularly?

<Megan, MS Nurse> Hi Tim. Yes, lots of people with MS find heat difficult. Damp heat seems to be worst. It depends on how you find the heat yourself - not everyone is bothered by it. Staying out of the sun wherever possible, wearing a hat, using a pocket fan when outside, lots of iced drinks and rubbing an ice cube on your pulse points can all help. Would your employers buy an air conditioning unit for your use? Employers can be sympathetic and will often do what they can to help

<John> Hi Tim, this won't be very helpful to you, but I used to fear the few very hot days we get. I managed to get air conditioning and it's a life saver on those few days

<Terl> Megan, When I eventually found out about amantadine it was my saviour but now I find that it is not as effective as it used to be. As it's named patient syndrome what would you suggest I ask my doctor for next?

<Megan, MS Nurse> Unfortunately there isn't much besides amantadine. There is a fairly new drug out which has come from the USA (surprise, surprise) called modafinil, which some people find very helpful. It may be worth a try

<Terl> Ta, Megan

<Chris H> I find reducing stress and self-expectations and being less ambitious helps

<Terl> Tim, I agree with John I have had A/C fitted downstairs and it is a godsend. Admittedly it was just over £1200 but worth every penny

<John> Yes, Chris H, I try and manage my expectations - on good days, it can help

<Chris H> I also take lots of vitamins, primrose oil etc and they seem to make my body stronger

<Gail Townsend OT> Chris H, I think the expectations we put on ourselves are often higher. Trying to reduce stress by a number of means including relaxation can help us feel "well"

<Chris H> I think psychology is 90% as medicines have relatively little to offer

<Terl> Just to prove the variety of MS there are I thrive on stress and adrenaline rushes!!

<John> Good luck, Terl - you do it your way, I'll do it mine!

<Gail Townsend OT> Chris H, I think as professionals (in the west) we are now coming to realise the importance of how we think and react is to our physical health

<Frank> I suffer from blurred vision, is there anything I can do to help this?

<Megan, MS Nurse> Hi Frank. I'm afraid it depends how long you have had the blurred vision. If it is a recent ,fairly acute onset, steroids may just help, although it is just as likely to settle down on its own given time. If the blurred vision has been with you for a long time, I am afraid it is more likely that you are stuck with it - although nothing is ever certain in MS. Visiting the opticians may help - although they can only correct for any usual deterioration. How bad is your blurred vision? Does it just come on when you're tired or is it there all the time?

<Gus> Hello, back after short break. Partly to see what's going on.

<Megan, MS Nurse> Hi Gus - glad you got back to us

<Simon, MS Trust> Gus, sadly you only see what happens after you log in. But we will be posting a transcript of the full session so you will be able to see everything.

<Megan, MS Nurse> Hi Midge - anything I can help with?

<Midge> How many MS nurses are being trained at the moment?

<Simon, MS Trust> The number of nurses has been increasing this year in line with the risk-sharing scheme, which is opening up access to the disease modifying drugs

<Megan, MS Nurse> I think there are about 140 MS nurses already in post and there are new people being trained up. I'm not sure how many. I know where I work in Manchester we are hoping to start 3 new MS nurses in the New Year

<Midge> I have no access to a nurse and I feel the facilities around my area are very poor for MS people (I live near Haslemere in Surrey). I did speak with a MS nurse once and boy what wonderful helpful people they are!!! I am so hoping one day I have one in my area.

<Megan, MS Nurse> I agree that we are extremely nice and helpful people - but then I may be biased! Sorry that you don't have one near you. I hope that in the future everyone with MS will have access to an MS nurse. The MS Trust, MS Society and the UK MS Specialist Nurse Association are all pushing for this

<Midge> Good to hear!!! Thank you. A physio question ... What ground rules for NHS use of a physio are there? I am secondary progressive used to have physio

<Simon, MS Trust> If you are able to be in the room between 3 and 7 we will be having a physio join us then

<Midge> Thank you

<Megan, MS Nurse> Midge, physio provision varies around the country but basically if your symptoms change, or if you are having particular problems eg with walking, balance, transferring etc. then a physio referral should be made. I

also try and ensure that anyone newly diagnosed also sees a physio at least once, although not all physio services will be able to accommodate this

<Simon, MS Trust> If you have access to an MS Therapy Centre, many of them provide physio - the website for the National Federation of Therapy Centres is at www.ms-selfhelp.org. This site has a list of the local centres

<Midge> Because I wear an EMS supplied by the Physio I don't have physio now. I had physio for 5/6 years previously. I was told I hadn't improved balance etc so they only check my timing and walking while wearing the EMS each 6 months

<Megan, MS Nurse> So long as the physio check things every 6 months you at least have a route back in. It is worth mentioning to them if anything has changed or become more difficult for you since you last saw them

<Midge> Thanks Megan. I'll come back to chat between 3/7pm

<Megan, MS Nurse> OK, hope you find it helpful, take care - and good luck with the MS nurses!

<Simon, MS Trust> Hello Sam, do you have any questions for Gail or Megan?

<Sam> Yes I do have a question. I am confused re: the issue of fatigue. For me it seems to be a symptom of "wanting to go to sleep". I do not really experience much "heaviness" of limbs and joints. It has been worse this last month and yet I'm so neurologically "well".

<Megan, MS Nurse> Sam, everyone will experience fatigue slightly differently and most people do have periods where the fatigue is worse and then it will settle down again - like most things in MS

<Sam> I don't feel that such fatigue is "justified" as such when I'm so well otherwise

<Gail, Occupational T> Many people find this time of year difficult. Partly it can be that we tend to be stuck indoors so we don't get much exposure to natural light, which affects our body clock. It might be that your home is warmer with the central heating on and that could be contributing to feeling more tired

<Megan, MS Nurse> One of the definitions of fatigue is that it is out of all proportion to any activity undertaken. It may be worth looking at other causes though too. Are you on any medications? Are you sleeping OK? Do you pace yourself? Have you noticed any particular triggers? Gail mentioned earlier in the chat about the importance of keeping a diary to monitor your fatigue and see if there is anything you can link it to.

<Sam> I think you're right about the wintertime as I'm better in the spring and summer. The tiredness just seems to fill my spare time, ie as soon as I get home from work, or all day if it's my day off. So I'm not sure that room temperature is the key.

<Gail, Occupational T> Often we can't make links without putting it into a structured format. You might be tired on your day off because you're trying to "catch up" from all your activity. Do you take breaks during the day? This can be hard to do at work

<Ann> I have a friend with MS and fatigue is her most troublesome symptom. She is quite interested in alternative therapies. What is your view on using alternative therapies to improve well-being and is there anything that helps fatigue specifically?

<Gail, Occupational T> Some people find using aromatherapy such as lavender oil helps them relax, so they feel better. It's important to look at what might be making the fatigue worse such as not sleeping, not eating well, doing too much

and so on. Everyone's different in what might be contributing and what they can do to manage it

<Megan, MS Nurse> Hi Ann, regards alternative therapies, the bottom line is if it helps, doesn't cause any harm and is not costing more than you want to pay then try it. As for specifics, I know that often injections of vitamin B12 from the GP every month can be helpful (not strictly an alternative therapy I know). I will just have a quick look through a book to see what other ideas there are...

<Gail, Occupational T> I agree with Megan, different things work for different people as far as alternatives go, the main thing is that it should do no harm. We talked earlier about the use of supplements and drinking things like camomile tea to help you sleep

<Megan, MS Nurse> Ann, having looked in the book [*Alternative Medicine and Multiple Sclerosis by AC Bowling, published by Demos (2001)*], there are lots of references to various alternative therapies that may help with fatigue. But as Gail says, it is important to check that there are no other causes for the fatigue besides the MS. Relaxation and meditation can be really helpful, as is pacing yourself and prioritising activities through the day. Appropriate levels of exercise can also help and it is possible to increase stamina over time

<Ann> Thanks. I know that she has been enjoying reflexology, but she could explore the benefits of aromatherapy and possibly meditation further I think. Also looking at how she structures her day. I think sometimes she takes on too much at once! Thanks for the other ideas - the vitamin B12 is something I haven't heard of before.

<Sam> I had raised a frustration/query over disproportionate fatigue. In answer to Megan, Gail and Ann: I do rest after work-usually with a nap. I'm on interferon (3 yrs) and B12 injections once a month. I go to yoga weekly (an MS group) and I try to walk briskly each week. Yet I just seem to be as tired!

<Gail, Occupational T> Sometimes fatigue can be brought on or made worse because you have stayed in one position for too long. As animals we're not designed for that, try and change position regularly and stretch and breath deeply for a few breaths. This can wake you up

<Megan, MS Nurse> Ann, vitamin B12 injections (it doesn't seem to work the same orally for fatigue) have unfortunately not been researched, but anecdotal evidence does show that they help about 3/4 people who try them. We usually ask GPs to prescribe an injection a month for 5-6 months. If after that time the individual has found them helpful and the GP is happy, they can be continued. If not, they are not going to work and can be stopped

<Ann> Many thanks for your help. I understand a transcript will be available of this whole day's discussion? I would like to pass on the info - and also read up on what I missed as I have to go out now. Thanks again.

<Simon, MS Trust> Ann, the transcript will be posted on the MS Trust website next week - along with transcripts of previous chatroom sessions

<Gail, Occupational T> Sam, you are obviously doing a lot of good things. Do you get a chance to take breaks during the day at work? Do you have to do the same thing for long periods of time?

<Sam> I suspect that I should fight the fatigue feeling and go for a walk instead of hitting the pillow! But it's so much harder to do. How are we to understand a healthy balance?

<Megan, MS Nurse> It is really difficult to get the balance right. There is fine line between pushing yourself and overdoing it, not helped by the fact that the boundary will shift day by day and even hourly. If you are feeling wrecked - rest!

<Gail, Occupational T> Sam, there's nothing wrong with having a nap after work. Fatigue isn't something you can "fight". You can end up more tired by doing that and make the fatigue last longer

<Sam> No. I don't rest at work, and it wouldn't be possible. But I do only work 4-5 hrs on 4 days. My main problem with all this is that I know I'm relatively well for a person with MS at present and I think I should be living life to the full while I can. Especially as I had a struggle to get the interferon

<Gail, Occupational T> Even if you can't take breaks how about changing position and stretching? If you have an office job is your chair supporting you properly? To get the most out of your days off as well as having a rest you could try planning some activity which is completely different to what you do at work to give your body and mind a break

<Megan, MS Nurse> Sam, interferon doesn't make you feel any better necessarily. It just cuts down the risk of further attacks. No one is going to stop you having the interferon just because you get tired. For many people with MS fatigue is their worst symptom and can colour everything. Have you tried any of the medications that can help? If vitamin B12 doesn't work, there is a medication called amantadine which is often very helpful

<Sam> I will try to change my position when tired at home. At work I'm active all of the time and I seem to be better for it. I have heard of amantadine I'm holding that in reserve. I don't think the B12 has made a lot of difference unfortunately

<Megan, MS Nurse> No unfortunately Sam vitamin B12 doesn't work for everyone. Amantadine is the next step with regards to medication and is usually pretty well tolerated so long as it is taken before 2pm (otherwise it can keep you awake!). But I understand your reluctance to rush into taking medications

<Gail, Occupational T> Sam, a lot of people say that about activity. In which case at weekends try and do things which may be less physically demanding, but are still enjoyable for you, and you don't feel you've slept the time away. Don't forget though that your tolerance for say reading may not be as long as a more physical activity, it's very individual

<Sam> Thank you all for your replies. I have probably got to come to terms with this aspect, just like I would have to accept a physical disability. Being 'invisible' affects the credibility of it, for me somehow.

<Megan, MS Nurse> Hope it has been of some help. The 'invisible' symptoms are often the most difficult to cope with - both for you and for others around you who find it difficult to understand and may have unrealistic expectations of you

<Gail, Occupational T> Sam, as you say it's invisible but it's no less real for that. Good luck, and you could try talking to an OT locally as well as they may be able to give you some suggestions that help

<Sam> Thanks again all. I'll sign off now. I look forward to reading the transcript and learning from other topics raised.

<Gail, Occupational T> Hello David D. Do you have a question for Megan or myself?

<David D> Do you know the names of any neurologists who specialise in primary progressive MS

<Megan, MS Nurse> I'm not sure of any who specialise specifically in PPMS. Any neurologist who specialises in MS (rather than epilepsy or Parkinson's disease etc.) should be able to help. Which part of the country are you from?

<David D> Hertfordshire

<Megan, MS Nurse> Just doing some checking. I understand there are difficulties accessing neurologists in Herts. In theory you should be able to request a referral to a neurologist out of area as the money should follow the patient. Either there is a good team at Addenbrookes in Cambridge, or at the Royal Free or the National in London

<Gail, Occupational T> Depending on where you live in Herts, patients sometimes use the neurologists in Buckinghamshire. But it may be as easy to go to London as across country

<Simon, MS Trust> Welcome back, Gus

<Gus> Back again. This may be out of scope of this chatroom, so ignore if overwhelmed with more pressing questions: I read on an MS Newsgroup things about Hughes Syndrome and about bovine myelin - I forget now in what context. Do you know anything about either and if/how related to MS?

<Megan, MS Nurse> Sorry Gus, I haven't heard of Hughes Syndrome and don't know much about bovine myelin. I have a feeling that the logic behind its use was to make the body stop attacking its own myelin but I don't think very much came of it - not to date anyway

<Gus> Someone on the MS Newsgroup says that a researcher reckons 30% of people with MS really have Hughes Syndrome, which prompted my question.

<Julie> Hello there. It's a bit difficult to come in at this stage when you don't know what has been discussed before!

<Gail, Occupational T> Julie, just ask away it doesn't matter

<Julie> My comment rather than question is that what I find probably most helpful is being not just positive as possible but more actually going out and helping others who are worse off - obviously depending on one's own condition. I did voluntary work before I was diagnosed but get even greater pleasure and encouragement now than then. And it can be quite simply chatting on the phone.

<Megan, MS Nurse> Voluntary work can be a great way to get out and about, bring some structure into the day, to use all the skills that people have and of course all the other benefits such as company and job satisfaction. There are many different types of voluntary work available as you say and I am glad you enjoy this

<Simon, MS Trust> That reflects something someone wrote in our recent book of *Tips For Living With MS*. Their idea was to join a voluntary group not involved with MS in order to give oneself a sense of perspective

<Gail, Occupational T> Julie, so many of our local voluntary agencies are desperate for volunteers, yet as you say it can be so good for the volunteer

<Julie> Yes, it doesn't have to be MS, although it's good to help others you can relate to in that way. But the wider the field the better and it really can put a perspective on things. One thing I do is bereavement visiting and it can be very rewarding.

<Gus> As you don't seem to be busy; going back to an earlier question I raised - most people I hear about with MS fatigue find it difficult to stay awake but I find that the worse the fatigue, the harder it is to sleep, particularly when I feel a nap for a while would re-invigorate me. Am I unusual?

<Gail, Occupational T> No you're not unusual, Gus. Sleep can be at its most elusive when you feel most tired

<Megan, MS Nurse> Did you see the earlier responses about getting yourself into a routine before going to sleep - using lavender oil and/or camomile tea etc?

<Gail, Occupational T> You could try other ways of recouping your energy through relaxation or meditation. In some ways trying to go to sleep can be

stressful. By using a formal relaxation technique you can help "switch off" your mind which can help you drop off

<Megan, MS Nurse> Gail is right - some breathing exercises or listening to a tape and doing some guided imagery/relaxation may be more beneficial than having a nap anyway

<Julie> Any suggestions for "restless legs" of the hot and burning kind? I've tried cooling gels but they only work very briefly, and if your legs are painful, it makes it pretty miserable in general, so guidance please!

<Megan, MS Nurse> Julie, this sounds like 'nerve pain'. This type of pain often comes and goes on its own. But if yours doesn't or is particularly troublesome, you may find something like amitriptyline or Tegretol helpful

<Julie> I was hoping for something other than drugs as I take quite a few for various other problems. Although there is a degree of coming and going, it is fairly constant and worsened by doing too much eg walking. It's difficult to get the right balance.

<Megan, MS Nurse> As you say, it's a matter of balance. Look for things that trigger the pain or make it worse such as fatigue, heat, too much walking etc, and try and minimise these. I don't know whether anyone else has any tips for how they manage their pain?

<Julie> Can anyone pass comment on the so-called euphoria of MS. I often seem to "suffer" from this, which leads to people commenting on how well I "cope". Is that perhaps the euphoria exists in order for you to do just that, cope? Sometimes think I'm a bit batty!

<Gus> Julie, can I have some of this euphoria, please?!

<Megan, MS Nurse> Euphoria is common in MS and as you say, it does help people to 'cope' very often, and often helps family and friends to cope too

<Julie> Gus, perhaps there isn't such a thing and I really AM batty!

<Gus> Julie, there IS such a thing. One of the big MS problems seems to be that everyone has different symptoms, though fatigue seems more common than other things

<Julie> Megan, yes but it does also give a misleading impression at times and then people expect you to do more than you can or not complain when things are bad.

<Megan, MS Nurse> That's true. As in all things relating to MS, it is a matter of balance and that's often one of the hardest things to achieve

<Gus> Megan, for about 15 years I've used Valium to 1) Help me sleep when fatigue inhibits sleep and 2) as the only thing of many I've tried that relieve disturbing "crawling" head sensations. I do not take it regularly/everyday. Do you see any problem with this?

<Megan, MS Nurse> I think that so long as you aren't taking it regularly or in large doses there should be no particular problems. Presumably your GP knows how you take it. I presume you have tried alternatives with no effect?

<Simon, MS Trust> Gail Townsend has now left the session, thanks Gail. Michelle Ennis, an OT, and Jenny Craig, a physio, have now joined as experts. Does anyone have a question for either of them?

<Ali> I am going to speak to someone later who has MS and runs pilates classes for people with MS. Any thoughts on the benefits of this?

<Gus> Thanks, Megan. Yes my GP OK's it (though maybe it's an easy answer for him). Yes, I've tried lots of other things. Ref Ali's query - what are pilates?

<Michelle (OT)/ Jenny (PT)> Pilates is something we often recommend. It has a number of benefits, from a physical point of view it can help maintaining muscle tone and improve posture. In addition to this it can be used for stress management as it is time for yourself and a form of relaxation. As with any of this type of activity, there is the benefit that you are doing something positive to help manage your condition, but you must make sure that you adapt the activity so that it is safe and pleasurable for you!

<Julie> It's also one of the more expensive systems, beyond my reach. I do find yoga of benefit though (and more reasonably prices) and seems to energise me for a few hours afterwards

<Ali> Thanks Michelle/Julie, not sure about the costs right now but will go and see. Better form of relaxation I guess than sitting watching the TV!

<Michelle (OT)/ Jenny (PT)> I am not aware why it should be expensive and is often available at sports centre or you can purchase tapes and books from which, having a background of yoga, you should easily pick up the techniques

<Gus> Signing off now; thanks for all your advice and best wishes to other contributors.

<Simon, MS Trust> Thanks for your input, Gus

<Julie> I think it's expensive because it's the latest trendy thing to do (for those keep-fitters rather than MSers)!

<Michelle (OT)/ Jenny (PT)> All we can suggest is to have a good 'shop around' until you find a reasonably priced class

<Dusty> Can you overdose on evening primrose oil? I have been taking 4000mg daily for about 8 months. I can't see that it is helping at all. Should I just give it up or carry on for longer?

<Megan, MS Nurse> Hi Dusty. I don't think there are any side effects but this is a massive dose and I feel it would be best if you just checked in with your GP

<Dusty> Thanks Megan

<Ali> Michelle/Jenny, I still work full time in the NHS. Any ideas how I can get my colleagues to give a bit more understanding about my good days/bad days? Sometimes I think they think I'm at it as my symptoms are mostly invisible?

<Michelle (OT)/ Jenny (PT)> This is a difficult one, which centres around communication and trying to explain symptoms. This can often be difficult to approach. Try explaining symptoms use booklets etc if needs be. One thing which is often hard to describe is fatigue. We have found people with MS sometimes say to others they are tired. People without MS immediately think about how they feel tired, which IS NOT like having ms fatigue. Try to talk about fatigue in terms of how it feels to you and not slip into talking about tiredness

<Megan, MS Nurse> Hi everyone. I have to go and catch my train now. Thanks to everyone for your input and for an interesting and far reaching debate. I look forward to seeing the transcript with Jenny and Michelles 'bit'.

<Simon, MS Trust> Thanks Megan

<Ali> Thanks Michelle. Signing off now maybe back later. Want to thank MS Trust for all the campaigning for interferon prescription on the NHS. Started on Avonex 10 wks ago.

<Tim> Hello, I was interested in the effects of living in a warm climate?

<Michelle (OT)/ Jenny (PT)> There is ongoing work in this field. I don't know the most up-to-date information on this, but there they think a climatic factor.

<Tim> Is there any material I could access?

<Michelle (OT)/ Jenny (PT)> People with MS sometimes find their symptoms feel a little bit worse temporarily when they are hot eg when exercising, or in a hot bath or hot country, but it is only temporary thing until the temperature cools down again.

<Tim> I am recently diagnosed. I hope to return to a climate that has monsoon for 4 months, max 33 centigrade. No air conditioning, desk work only

<Michelle (OT)/ Jenny (PT)> MS Society or MS Trust both have literature available on this type of topic I believe.

<Simon, MS Trust> Yes, if you send your postal address to us at info@mstrust.org.uk, we can look out papers and relevant material for you

<Michelle (OT)/ Jenny (PT)> Not everyone is affected by this temperature thing. If heat is a problem for you, you will just need to make sure you take steps to try to keep your temp down, such as a fan, cold drinks, cool clothing, plenty of rests.

<Tim> Thanks

<Jeff> Hello. New to this

<Simon, MS Trust> Don't worry. Do you have a question?

<Jeff> I read a lot about all manner of alternative ways of coping with MS. Some sound interesting, some sound plain mad. Do people have opinions on what is worth investigating? What have other people tried that helped or didn't?

<Michelle (OT)/ Jenny (PT)> It very much depends on what type of symptoms you are trying to cope with.

<Jeff> fatigue, bladder, some stiffness in my legs

<Michelle (OT)/ Jenny (PT)> There are some very useful self-help strategies out there but for these symptoms there are some very good self-help and medically based interventions, which, when used together, can be effective. For bladder there are a few options including medication and changes to fluid intake and if possible you should discuss this with an MS nurse or GP/ continence nurse. For fatigue, there is a very complex array of approaches from medication such as amantadine through to changing lifestyle in small ways, as well as trying to maintain activity levels, good nutrition and trying to achieve a balance between activity and rest.

<Jeff> I am keen to look into things that aren't drug based if possible

<Michelle (OT)/ Jenny (PT)> With regard to leg stiffness, medications such as baclofen can sometimes help, as can a gentle stretching programme for your muscles which a physiotherapist can teach you to do yourself. For fatigue, the key is in lifestyle management and drugs can often only supplement this. Examples of changes to lifestyle can include planning carefully how you use your energy, prioritising jobs to be done, delegating things to others and placing exercise and time for relaxation and rest as priorities. Also for stiffness, looking at the way you move in a general way eg posture or balance and making changes to this can help a little.

<Jeff> Can you tell me more about stretching exercises?

<Michelle (OT)/ Jenny (PT)> These are generally gentle movements which take muscles to the end of their 'range'. They should not be painful. There are specific ways to approach these and they should be taught by a physiotherapist initially but then they can be undertaken by yourself or another person. They need to be done regularly for them to be of benefit

<Jeff> That sounds good (if I can make myself do it) - but access to a physio is difficult sometimes

<Les> One of the challenges that I used to have was trying to mow the lawn before my energy expired. I worked out that if I placed a chair on the patio, I would sit down and rest as soon as I started to feel tired. Once I had rested for 5 or 10 minutes, I was able to complete the task without getting completely knackered!

<Michelle (OT)/ Jenny (PT)> Les - thats a good strategy to adopt - not only for gardening but lots of other tasks - take rests. Jeff, you only need a one off appointment for the education. If this not available in your area, it may be worth considering a private physio for this one session

<Simon, MS Trust> Jeff, do you know about MS therapy centres? Many of them have physios. You can search for one near you at www.ms-selfhelp.org

<Jeff> When you say good nutrition, is there anything special I should be eating because of MS?

<Michelle (OT)/ Jenny (PT)> Not anything specific. What is advocated is a general healthy diet - the same that applies to all of us. Of course if you have any other medical problems these must be considered and if for example you have bowel problems a change to diet can sometimes help.

MS nurses or Continence Nurses can give more advice on this.

<Jeff> You read things about cutting out wheat, or dairy products, or meat, or almost everything. Is there anything in these?

<Michelle (OT)/ Jenny (PT)> There are lots of 'faddy' diet stuff around related to MS but there is no evidence for the benefits from any of these and if not undertaken with sound advice they can be potentially not good for you in the longer-term. The MS Society and MS Trust both have good literature on this - see Simon

<Simon, MS Trust> Yes, contact us at info@mstrust.org.uk and we'll look out some information for you.

<Jeff> thanks

<Simon, MS Trust> Hello John, do you have a question?

<John> I recently went swimming but felt much worse afterwards. Is this bad for me?

<Michelle (OT)/ Jenny (PT)> Swimming is not bad for you. You obviously need to go gently with this activity and it may be that you overdid it on the occasion you went. I'd suggest you try again but literally only do a few minutes the first time. Then, if you feel okay, you can build it up slowly. Swimming or exercise in the water is one of the best ways for people with MS to get some aerobic exercise.

<Jeff> Can you explain what aerobic exercise is? Are there non aerobic exercises that aren't so good for you (excuse my ignorance)

<Michelle (OT)/ Jenny (PT)> Aerobic exercise is something that you do that increases your heart beat and your breathing rate and so increases your fitness. Non aerobic exercise tends to be things like a strengthening muscle programme from a physio which although is good for you and should be done regularly will not necessarily effect your fitness level. Best is a combination of the two types. Aerobic activity can be anything that fits into that group.

<Jeff> Presumably things like swimming and walking do this, or do you mean more gym type exercises?

<Michelle (OT)/ Jenny (PT)> Yes, walking upstairs, gardening, washing the car or walking to the paper shop! Swimming and walking are more aerobic, although in water you can do specific strengthening or stretching exercises too.

<Jeff> Shame that washing the car fits - I was looking for an excuse :-)

<Michelle (OT)/ Jenny (PT)> A gym can have a combination of both aerobic and non-aerobic exercises. The treadmill and exercise bike are aerobic and the weights are strengthening. No excuses Jeff, exercise and activity is good for you!! So long as you are sensible with it and don't go too hard with it especially initially.

<Jeff> Presumably starting slowly and building up?

<Michelle (OT)/ Jenny (PT)> Yes, any new activity you do (or take up an old one!) you should always start off very gently - so gently you feel like you have not done much. You can see how your body reacts to that and if it copes okay - start to slowly build it up. Caution with doing weights for strength as if not done carefully or properly they can increase your stiffness.

<Jeff> Is it possible to distinguish between MS stiffness and stiffness from having done exercise (or are they the same thing in different guises?)

<Michelle (OT)/ Jenny (PT)> They are different. Post exercise stiffness usually comes on in the muscles 12 - 24 hours after a new type of muscle activity, builds up to 36 hours, then slowly goes away again by about 48 hours. If it stays longer than this it may be MS stiffness. Also if you repeat the same activity again, the post exercise stiffness will be less significant as your muscles are more used to it. If it is MS stiffness the stiffness will probably be the same the second time as it is the first etc. This doesn't mean you shouldn't do the activity - just be aware of the potential problems that the MS stiffness may give you in the short term and don't overdo it. Never do heavy weights - only very light ones and increase the number of repetitions you do instead.

<Jeff> So it's sort of trial and error and being careful with new things

<Michelle (OT)/ Jenny (PT)> That's exactly it. Try it and see what happens - if it doesn't work for you TRY SOMETHING ELSE!

<Jeff> Thanks - no excuses anymore :-)

<Michelle (OT)/ Jenny (PT)> No - no excuses. But do go carefully. Start with one activity then gradually introduce others over time.

<Simon, MS Trust> Hello Bill - do you have a question?

<Bill> Yes - I'm a bit vague. What is wellness? Or is it just a sort of umbrella term?

<Michelle (OT)/ Jenny (PT)> Wellness is related to feelings of physical and emotional well-being. It can be considered as an umbrella term for activities such as exercise, managing stress, having a good diet, looking after your general health and making positive changes to your lifestyle in order to manage your MS. It is also concerned with looking beyond MS to your general physical and emotional health.

<Bill> I've been depressed since I got MS - are there things you can suggest to help with this?

<Michelle (OT)/ Jenny (PT)> 'Depression' can cover a whole spectrum of feelings from feeling 'down and uncertain' to feeling very low in mood and having the accompanying recognised physical and emotional symptoms of the condition 'depression'. Things to help with this will depend where you feel you are on this scale. None of these feelings are wrong or strange to experience when living with MS. Common approaches to help are finding people to talk to, either somebody within your family and friends or a professional for this purpose.

<Bill> It's probably a mixture of both things - feeling down because of the MS and then not being able to pull myself out of that dive

<Michelle (OT)/ Jenny (PT)> Trying to maintain a positive attitude through marinating positive experiences and using self-management techniques, gaining a support network, exercise can sometimes help to increase mood a little.

<Bill> You don't want to burden people with this. It's hard to find people you feel you can offload on

<Michelle (OT)/ Jenny (PT)> Stress can often lead to low mood, so if this is an issue, consider stress management techniques. And of course there is a role for medication in these situations. Do you feel that a support group could offer what you need, or maybe you could consider counselling - just to talk through your feelings with somebody you won't feel you are 'burdening', although they probably don't see it as a burden

<Simon, MS Trust> Hello Lorri, do you have a question?

<Lorri> Does anyone know where I could purchase/view a single handed keyboard?

<Michelle (OT)/ Jenny (PT)> There is an organisation called AbilityNet. They will advise on all computer adaptations. They are a national organisation.....you can call them on... I only have the Liverpool number which is 207 0600 and they can put you in touch with your local group.

<Simon, MS Trust> The AbilityNet website is at www.abilitynet.org.uk

<Michelle (OT)/ Jenny (PT)> Thanks for that, Simon. That's probably easier than calling!

<Lorri> Thanks I'll try there

<chi-town> I have a question about exercise. The contradiction of fatiguing quickly and suddenly and how to get exercise and maintain strength

<Michelle (OT)/ Jenny (PT)> Chi-town - it is difficult to get the right balance. It is important when you exercise that you take plenty short rests before you get to the point of fatiguing. This allows your muscles a short recovery time and then you can carry on for a bit longer. Then rest again etc

<chi-town> I'm afraid if I use my energy for exercise, I won't have any for normal daily stuff.

<Michelle (OT)/ Jenny (PT)> Again its about finding the balance and REALLY prioritising the normal daily things. For example regular exercise will help to maintain your fitness level, then the things you do day to day eg shopping, housework or working will be that little easier.

<chi-town> Yes, prioritising is a delicate balancing act. I fail frequently and can't make supper.

<Michelle (OT)/ Jenny (PT)> When prioritising it is important that you get the balance of things that are enjoyable for you and those things you have to do.

<chi-town> Right. I'm becoming conditioned to perceive it as a positive thing to delegate and get help, but then, am I cheating myself out of the exercise I need?? I can enjoy laundry if I feel good.

<Michelle (OT)/ Jenny (PT)> You do need to delegate the less important things to you so that you have time and energy to do the important things to you, and hopefully one of these things would be exercise!

<chi-town> Right. Probably need to establish a routine.

<Michelle (OT)/ Jenny (PT)> Yes, routine in MS is one of the key factors in self management. Finding routines that work for you and those around you but still taking into account the normal fluctuations in your MS

<chi-town> I just started Avonex last week. It seems like the subsequent day is pretty well shot - feel run over by a truck

<Michelle (OT)/ Jenny (PT)> I think this is not uncommon and maybe this 'bad day' needs to be planned into your routine. Don't plan anything too strenuous for this day.

<chi-town> For sure, and thank y'all.

<Aly> It's tricky isn't it. My sense of well-being comes from being busy and on the go, but MS doesn't allow this all the time

<Michelle (OT)/ Jenny (PT)> Hopefully by getting the balance right the times you cannot be busy will be less.

<chi-town> And it's so startling, because you feel well and expect to do things in the day and then, suddenly are wiped out and forget it. It's not possible.

<Michelle (OT)/ Jenny (PT)> Also think about some things you can still do when energy levels are low, which will still make you feel happy.

<chi-town> Right, like have a plan "B". That IS a terrific idea - and have it already in place before feeling exhausted.

<Aly> I know, chi-town! You try to pace yourself but get caught up in things and then bang!

<Michelle (OT)/ Jenny (PT)> It is also important for us all to learn to stop and relax from time to time, not just people with MS

<chi-town> My family always says stop and rest before you are exhausted, but it just comes without warning!

<Aly> I find it hard. Before MS I was always on the go and it is so difficult to reel myself in if I feel Ok

<chi-town> EXACTLY - Aly!

<Michelle (OT)/ Jenny (PT)> From what you are describing this sounds like specific MS fatigue (known as lassitude fatigue). This 'wave like' fatigue is unique to MS and is not related to activity undertaken or sleep etc but is a specific symptom of MS.

<Aly> But boy do you feel it when you go to far! I should learn my lesson but often don't

<chi-town> I truly wonder if we've done ourselves harm if we kept functioning till we get tired.... feel like having made a mistake.

<Michelle (OT)/ Jenny (PT)> When this comes on the best thing to do is rest completely. It should resolve within an hour or so. Don't be too hard on yourself and try and fight it. I think the important thing is too separate when you feel 'tired', which can be helped by pacing yourself and taking breaks, and this overwhelming which comes on without warning - for which you need to rest

<chi-town> Now that is true about it resolving - it often does! And that is wonderful, albeit a bit puzzling

<Aly> My old self was never say die, keep on fighting, etc. The post MS me finds it hard to shake that sometimes

<Michelle (OT)/ Jenny (PT)> It is difficult, but try and work with it rather than fight against it - because this way nobody wins!

<Tessa> I wondered what your views are on diet and MS? I have been following a gluten free, yeast free diet and have noticed some improvements but am not sure if this is just the nature of the illness

<Simon, MS Trust> Tessa, how long have you been following that diet?

<Tessa> I have been following a gluten free diet for 8 months and yeast free for 2 months. I have always been interested in health and diet since I was diagnosed and excluded wheat for many years previously

<Michelle (OT)/ Jenny (PT)> Tessa, we would agree. There is no way of knowing whether this is related to your diet or the nature of your MS. There is no substantial evidence in favour of your diet. Hopefully you are undertaking this with medical supervision

<Aly> I looked at that, Tessa. It seems to cut out so many things and I like my food *s*. Are the benefits worth the things you can't eat anymore?

<Michelle (OT)/ Jenny (PT)> Aly, we are not aware of any substantial benefits in this type of diet. If the foods you enjoy are healthy type foods - carry on and enjoy!

<Tessa> I have taken advice from a nutritionist. There are many ways to liven up the diet. It does however take care to make sure you are getting all the right nutrients and I take supplements. At the moment I would say, yes the diet is worth it since I have experienced improvements in my mobility, and other unrelated MS health problems such as eczema and IBS. So for the moment I will stick to my diet

<Michelle (OT)/ Jenny (PT)> Tessa, that's fine. Just get this checked with a doctor from time to time

<Tessa> Thanks Michelle/Jenny

<Julia> Has anybody here heard about the recent report from scientists that MS ISN'T caused by attacks on nerve coating but something to do with "support cells"?

<Michelle (OT)/ Jenny (PT)> We have heard of this but there has been a response to this by other researchers. Suggest the MS Trust and the MS Society will have the most up to date info.

<Simon, MS Trust> Yes, we have a copy of the paper that looks at this (I can send a copy if you'd like to see it if you send your postal address to info@mstrust.org.uk). The paper isn't quite as sensationalist as some of the news reports it generated

<John> Do you have any views on whether music can help well-being for people with MS and, if so, which music?

<Michelle (OT)/ Jenny (PT)> John, not been asked this before! In terms of managing your MS, I feel it can be useful in relation to reducing stress and general positive feelings if music is something that you connect with.

<John> Thanks Michelle/Jenny, music and I are ok!

<Julia> Have you seen the website called MS Elimination?? I took a look and was baffled... what's that about?

<Michelle (OT)/ Jenny (PT)> Julia, not seen it, sorry

<Simon, MS Trust> Julia, don't know that one. What does it say?

<Julia> A whole lot a stuff that would take a professor to understand!!! I unjoined in a flash!! Do you think you could investigate the site and report on it in newsletter??

<Simon, MS Trust> Julia, I'll have a look. Veering off topic, but one of the things I'd like to include next year in Open Door, our newsletter, is a brief guide to immunology for people with MS. It's an easily baffling area but something the could do with laying out simply (if I can find someone who can do that!)

<Julia> OK, thanks

<Simon, MS Trust> Hello Paul. Do you have a question for either Michelle or Jenny?

<Paul> I just want to know if I am doing everything possible to slow down my MS. I have primary progressive. Its in the early stages I have minor disability in my legs

<Michelle (OT)/ Jenny (PT)> It is difficult for anyone to know how your MS will progress. However it is important to maintain activity levels as best you can, as well as keeping your attitude to MS as positive as possible.

<Julia> Could anyone tell me about baclofen for spasms?

<Michelle (OT)/ Jenny (PT)> Julia, baclofen is a widely used medication for spasms and often works well in combination with a regular stretching programme. You are best to speak to your GP or neurologist.

<Julia> OK, thanks.

<Paul> My specialist told me to eat red fruit and take evening primrose oil. Is there anything else I could take that might help?

<Aly> Red fruit? Strawberries and raspberries? Does that help? I like that idea

<Michelle (OT)/ Jenny (PT)> Paul, there are no specific supplements for MS other than a balanced diet which gives the full range of vitamins and minerals.

<Julia> Going back to the positivity, I adopted a very positive attitude on my first major attack and found that I made a VERY speedy recovery. A positive attitude is EVERYTHING

<Aly> Positive pays dividends, Julia, but is so hard to hang onto when everything seems to be stopping doing what you want it to do. But worth the effort to cling onto it

<Michelle (OT)/ Jenny (PT)> A positive attitude can help deal with impact of MS, glad you have found ways of marinating yours, Julia.

<Paul> So I need to keep as active as I can and keep a positive attitude

<Julia> OK, maybe I'm speaking too soon because ever since I started Betaferon I haven't had so much as a cold!! I feel bad now!

<Michelle (OT)/ Jenny (PT)> Aly, you're right it is hard. But there are ways to actively try and maintain a positive attitude, such as looking for alternative things you can do which make you feel good or changing the way you do things and not looking at things in all or nothing terms.

<Aly> It sound too simplistic, doesn't it, Paul, but that does seem to work for me

<Paul> How come my doctor says beta interferon is not suitable for me ?

<Michelle (OT)/ Jenny (PT)> Sorry Paul, without knowing you or your MS course it is impossible for us to say.

<Paul> OK thanks. I am only learning about MS. I've only known for 4 months

<Michelle (OT)/ Jenny (PT)> There are criteria for this (which are no longer related to financial restraints) so ask your doctor to explain his decision to you. It is important you understand this Paul. These are early days, please don't be afraid to ask and ask (and ask) all your questions so that you have the information you need to help you deal with this new situation. Good luck

<Paul> OK thanks

<Julia> I think I bugged everyone with questions all about what exactly was going on in my body when I was first diagnosed. I'm glad I did because it helps me to understand my disease!

<Michelle (OT)/ Jenny (PT)> Understanding what MS means and how yours behaves is a key in managing and coping with it in the long term. So don't be afraid to ask all the questions you need

<Aly> Good for you, Julia! At first I was worried I was pestering people but then realised I needed to know things and they could tell me. Knowing has helped me more than sitting quietly at the back

<Carole> I belong to a local gym who don't seem to know a lot about MS, how can I help?

<Michelle (OT)/ Jenny (PT)> Often gym instructors etc have very little training in different conditions. I'd suggest having a chat with them (ask to do it privately away from the gym room if you prefer) and try to explain a little bit about your MS to them. Also use some of the MS Trust or Soc literature to help them. You know your MS best of all and are best placed to educate them. And that may help other people too. They will likely appreciate the knowledge, as it is probably a little bit frightening for the instructor too!

<Julia> I have had loads of fun educating people on my MS because they haven't a clue!! Kind of like teaching babies! ha ha

<Paul> I just wish I knew how bad it was going to get. It's got no worse in a year. I've known it was MS for 4 months

<Aly> Not knowing is hard, isn't it Paul. But then, a few years back I didn't know I'd have MS at all. It sounds a bit twee, but you do have to live for today as much as you can

<Paul> Yes Aly, thanks

<Carole> I could do with some guidance about how to build up my stamina so I could walk further

<Simon, MS Trust> Carole, a while ago we published an article in our newsletter by an exercise consultant (?) about how he planned an exercise regime around the individual needs of someone with MS. If you let me know your postal address (send it to info@mstrust.org.uk) I could send you a copy

<Charles> Aha, a physio! Is there any other form of exercise to use alongside my physio ones that have given me back stability and have helped beyond belief. I am not too sure how hard to push myself

<Michelle (OT)/ Jenny (PT)> Charles - there are a few different types of exercises that help back stability - such as pilates, yoga or Muscle Imbalance techniques. It depends whether you mean specifically other back things or exercise in general. You probably need to go back to your physio and discuss again. Don't push tooooooo hard in exercise - moderation - a little and often is best approach.

<Julia> I was sent for physio when my hands felt very tight, but how come I get sent there when its a signal transmission problem not a physical one?

<Michelle (OT)/ Jenny (PT)> Often people are sent to physiotherapy in order to maintain range of movement and prevent secondary weakness. This comes about when we get some problem with for example our hands, which means we don't use them as much. They can become weaker. This is a muscular problem not transmission, so physio was about preventing any additional problems to those produced from your MS. Obviously physio cannot attempt to reverse the transmission problem.

<Julia> Oh, I see. I couldn't stop stretching my fingers back to try to ease the feeling and was told I might damage something in my hands, but I had to roll putty in physio, which was pretty painful too!!

<Michelle (OT)/ Jenny (PT)> Stretching is okay so long as its gentle and not putting too much pressure on your fingers. Often the tightness is accompanied by increased sensitivity and touch/rolling things can be a little bit uncomfortable but not damaging and helps to desensitise the area.

<Simon, MS Trust> We'll have to end the session in twenty minutes - does anyone have any more questions?

<Julia> OK thanks for the chat. I'll go and get myself a coffee. Bye and good luck to all!

<Simon, MS Trust> Thanks for your input, Julia

<Sam> Has Paul heard of or seen the MS Trust message board? I thought he might find he could ask questions and get support?

<Simon, MS Trust> Thanks for the plug, Sam. The MS People UK discussion list is available via the Information Services page of our website. Although hosted on our site, it is pretty much an autonomous group of people with MS comparing notes, offering support and an empathetic ear. If you have problems or questions, a wide range of experiences of MS are represented there

<Carole> Do you recommend any vitamins or particular foods?

<Michelle (OT)/ Jenny (PT)> Not really. We tend to recommend an all round general healthy diet and as long as you are doing this, specific vitamins etc are not thought to be necessary. As far as food again there is no evidence to say that any foods are 'good' for MS and also any specifically 'bad' for MS, so we don't recommend any specifics other than plenty of fruit, veg fibre and sufficient carbohydrates, proteins. Watch the fat intake but don't cut it out completely as some fats are needed in your diet for good health.

<Carole> Could you recommend any alternative therapies like reflexology for example? I have just started having Shiatsu massages, which I am finding very relaxing

<Aly> I like the sound of reflexology - I do hope that helps. Aromatherapy too

<Michelle (OT)/ Jenny (PT)> Alternative therapies certainly have their place in dealing with what MS throws at you. There are many different ones and some are a bit weird and wonderful. Things like aromatherapy, massage, reflexology and reiki are quite useful in helping with certain symptom managements and as a stress reliever, but please beware - don't set your sights too high. They do not act on the actual MS, only the symptoms. Also be wary of anything charging high prices!!! Some of these are unresearched and thought to be of little benefit. Before staring any of these have a chat with a healthcare professional just to check it out.

<Carole> I have found that I have lost a lot of self-confidence. Is this very common? Could you recommend any help with this?

<Michelle (OT)/ Jenny (PT)> Yes, it is common. We often gain our confidence through stability in life and knowing our roles and abilities and placing ourselves in challenging situations in which we achieve. Unfortunately MS can impact on our lives so that stability is hard to find. So don't be hard on yourself. Try and turn the situation around - think about how you have coped with your MS so far and look on this as a vast achievement. Think about the admiration you would have for someone else in your situation. This may help you have more confidence in yourself. Start building your confidence up with achieving very small goals initially. The first step is always the hardest.

<Carole> Thanks for your comments

<marcus> What constitutes a relapse? My neurologist is looking for evidence of one before February 2003 in order to forward me for tests with beta interferon. The MS nurse said that a relapse could be just for a day

<Michelle (OT)/ Jenny (PT)> Relapses in our centre are felt to be change in symptoms or presenting with new symptoms which last more than 48 hours in the absence of other medical presentations such as infections. But there is variation in this in different places.

<Simon, MS Trust> Marcus, if you send your postal address to me at info@mstrust.org.uk, I'll look up some definitions and information for you if you like

<Simon, MS Trust> I'm afraid we're going to have to wrap up the session now. Thanks to Michelle and Jenny and to Megan and Gail who were the experts earlier in the day

<Michelle (OT)/ Jenny (PT)> Bye, thanks for all your questions

<Simon, MS Trust> And thanks to everyone who took part