Progressive MS

Chatroom

25 September 2008

www.mstrust.org.uk

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Progressive MS

25 September 2008 - 10am to 7pm

- **Wendy Hartland -** *MS nurse*
- **Vicki Matthews -** *MS nurse*
- **Alison Smith -** *MS rehabilitation nurse*
- **Alan Izat -** *MS nurse*

This chatroom is an open forum and so the views expressed by participants are their own and are not necessarily those of the MS Trust.

A list of publications and resources mentioned in during the chatroom and a glossary of terms are available at the end of the transcript

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

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Simon - MS Trust: Welcome - the chatroom is now open.

Eileen: Is there any medication available yet for secondary progressive multiple sclerosis symptoms?

Wendy - MS nurse: Hello Eileen, there are lots of medications available for symptom management. Is there any particular symptom that concerns you?

Eileen: Every time I go to my review at hospital they tell me the same old thing - there is nothing available for secondary MS. I tell them about new drugs out but they still say it doesn't work for this condition stage.

Wendy - MS nurse: I appreciate it can seem pointless going for an annual check up only to be told nothing new can be done. Don't give up hope. Research is taking place all the time. If your neurologist has lost touch with you, you can't be offered new treatments when they do occur.

Viv: Are there any alternative therapies recommended for primary progressive MS?

Wendy - MS nurse: As far as I am aware there are no alternative therapies recommended, but that doesn't mean that some people don't find them helpful. Generally, anything that makes you feel good is worth a go, eg relaxation and massage, as long as there is no other medical reason why you can't try it.

Jane: Para 1.7.20.1 of the NICE Guidelines for the management of MS in primary and secondary care says "People with MS should be informed that there is some evidence to suggest that [seven items listed below] might be of benefit, although there is insufficient evidence to give more firm recommendation". The list includes reflexology, massage and body work.

Wendy - MS nurse: Thanks Jane.

Simon - MS Trust: You can order a copy of the NICE Guidelines from the MS Trust at 01462 476700, info@mstrust.org.uk or online at www.mstrust.org.uk/publications.

Jenny: Why is it that we hear so little about primary progressive MS in publications?

Wendy - MS nurse: There is actually quite a lot being written about primary progressive MS in the medical journals. I agree that more publicity is given to relapsing/remitting MS, but that doesn't mean other types of MS are being forgotten.

Simon - MS Trust: Jenny, the MS Trust is in the early stages of thinking about a book on progressive MS. This won't be available until next year at the soonest, but if people would like to offer help at the review stage, they can email us on info@mstrust.org.uk.

Jenny: Thank you Simon, I'll do that. By the way, this is the first time I have been in the chatroom and I think it is great! Keep up the good work.

Sandra: I was diagnosed in October 2005. The jury is out on whether I have primary progressive or relapsing-remitting. I haven't had any clearly defined relapses, rather a very gradual increase in new symptoms and very slow but noticeable increase in the impact of existing ones. How do I know which form of MS I have, is it purely a matter of time?

Jenny: Carrying on from Sandra's question, can the type of MS you have switch from one type to another at any time?

Wendy - MS nurse: Hello Sandra, once your neurologist has done all the relevant tests and investigations, plus taken a detailed history, it can be a matter of time. Sometimes people have very clear cut episodes from the beginning which make things more clear cut, but the actual type you have tends to be decided retrospectively.

Simon - MS Trust: A proportion of people with relapsing/remitting MS will find their MS eventually becomes progressive. This is called secondary progressive MS. Some people will find their MS is progressive from onset. This is primary progressive MS.

HellMS: I have primary progressive MS quite difficult to move about but if I'm sitting down 'I look really well'. I had my four minutes with my consultant and I am managing this hellish disease with pure willpower!

Wendy - MS nurse: I wish I had a pound for every person who tells me how annoyed they get when people tell them how well they look and they feel lousy! I tend to tell people to try and keep as well as they can, so that when something does come up, they are still well enough to benefit from it.

HellMS: Cheers Wendy. Just to know we are not the forgotten part of this 'Cinderella disease'. Pain is my biggest problem and if I take all the drugs suggested, I can't function. I'm still managing to work three days a week. 12 October will be my first anniversary of joining this exclusive club.

Wendy - MS nurse: If pain is a big problem, but the side effects are even worse, it may be worth asking for a referral to a pain clinic. Neurologists and pain specialists should complement each others' work.

Chris: Why are people with primary progressive MS routinely excluded from trials? Conventional wisdom has it that the drugs being tested "won't work for primary progressive MS" but this is demonstrably untrue. Is it that NICE have determined that because the drugs would be LESS effective for us with primary progressive MS, that therefore Primary Care Trusts will not be permitted to prescribe them for us? Isn't it therefore true that we are excluded from trials not for medical reasons, but for political reasons? Will the MS Trust address this appalling injustice on our behalf?

Wendy - MS nurse: Hello Chris,

People with primary progressive MS are not routinely excluded from trials. There are trials underway (unfortunately I think they are already full) for people with MS. A lot of the drugs target inflammation. As some people think inflammation may not be the main problem with primary progressive MS, these drugs are not always appropriate. I am not out to defend the Government, but I genuinely believe it is not about cost. Any Government would be foolish not to help people stay well and in employment for as long as possible.

Simon - MS Trust: The MS Trust would certainly support more openness in letting people know what trials are available that they could take part in, particularly those that might have benefit for people with progressive MS. As Wendy says, it's about the right type of research. The high profile trials connected to controlling inflammation (which is associated with relapses) aren't appropriate for people whose MS is progressive. Trials of neuroprotective drugs (eg CUPID) or repair techniques (where stem cells may have a role eg current work in Bristol) will probably be more relevant to people with progressive MS. Work is at a much earlier stage in these fields so research trials are often quite small and fill up quickly.

Chris: I hear what you say, but it just doesn't seem to be the case in my experience. I've simply lost count of the trials I have been excluded from - one or two didn't even make it clear until I had reached the final page of registration on their website, not having stated it beforehand. The only one I could have participated in was the cannabis trial, but in the end even that was closed to me - I was told I would not be able to drive during the months-long trial and as a rural resident, that would have made me housebound.

I now feel quite bitter and angry about this, and feel that primary progressive MS is the 'forgotten' end of MS, and that we have been more or less abandoned to our fate. That may not be the actual truth, but that is what it feels like.

(And what a relief that you have provided a forum for me to express this publicly. I hope there are politicians and neurologists reading this ...).

HellMS: I agree with Chris, I didn't want to seem negative but I am bitter and angry.

Wendy - MS nurse: Chris, don't think people don't care about primary progressive MS and secondary progressive MS. Personally, I think it is very interesting and a challenging area to work in and there are a lot of people who agree with me.

Karen: Sorry Wendy but I cannot agree with your comment about the Government not standing in the way of access to drugs. I have been using an unlicensed drug for two years. It has cost me £20k. It is keeping fit enough to work and has also improved some MS symptoms but the government won't fund it.

Wendy - MS nurse: I would be interested to know what the drug was. I appreciate it if you don't want to say in this chatroom.

By the way, don't be sorry for disagreeing with me. I don't pretend to know all the answers and the chatroom would soon get very boring.

Karen: Aimspro.

Geoff: I read somewhere about them trying to get trials going for Aimspro but haven't heard anything since. Do you know if they happened?

Karen: Aimspro trials started 10 August 10 this year.

Geoff: Great. Is that looking at progressive MS?

Karen: Secondary progressive MS for bladder dysfunction.

Wendy - MS nurse: Thanks for sharing that with us. I have only had one person try it so far. Unfortunately it didn't suit them. Then (if I remember correctly) the trial was stopped due to drug storage problems.

Karen: That's right, Wendy. It has to be injected as soon as it thaws out but the hospital concerned weren't following protocol - or whatever it's called. With my GP's support I tried to get funding for Aimspro through my PCT. They refused. I appealed. They refused again.

Karen: How can we get onto trials for new drugs? I'm willing to try anything.

Wendy - MS nurse: When new trials are due to start, the drug companies will often contact neurology centres and give a guide to help people get recruited onto them. Let your centre know you are interested. This may involve travelling to different areas. You can always contact the centres yourself, but you may later need a letter of support from your GP or neurologist.

Wendy - MS nurse: Just a general question to the group. Do you all see a neurologist, or do some of you prefer to see a rehabilitation consultant?

Karen: I don't see anyone. Nobody is remotely interested in MS.

Wendy - MS nurse: Sorry you feel that way Karen. As I said earlier, even if you feel it is a waste of your time now, I would encourage everyone to keep their annual appointments. If we don't know you are out there, when something does come up in the future, we won't be able to offer it to you.

Brian: I felt the same. I had a disinterested neurologist and I got the impression there was nothing out there. Then I got referred to someone who knew a bit about MS and was put in touch with an MS nurse. I still feel at the fringes, but now have people to offer some support. I think it's about getting to see the right people.

Karen: The neurologist who diagnosed me told me he could do nothing for me and there was no point in further appointments. I think MS patients are just supposed to 'go away and die' - preferably quietly.

Brian: That's just a rubbish neurologist. Find someone else.

Karen: Yes, I know. Even my GP says so. She reckons they are all useless round here.

Sandra: I see my MS nurse regularly (every three months or so) for regular reviews. Only ever saw the neurologist for my first referral then again on diagnosis day. I would sooner see the MS nurse than neurologist any day! She listens to what I have to say and how I feel and offers constructive advice and support.

Chris: Hear, hear Sandra - the MS nurse here is 100% excellent, and more effective than most other agencies combined. I see a neurologist but it is a complete waste of time. I've not even heard of a rehabilitation consultant - what is that?

Wendy - MS nurse: A rehabilitation consultant focuses on making the most of what you have now and preventing disability in the future. The ones in my area are excellent and I sometimes think for people with progressive forms of MS they are as useful, if not more so than neurologists. Oops, that's me in the Job Centre on Monday!

HellMS: My consultant is apparently is an MS guru! I was singularly unimpressed with my four minutes - 'You'll have read about primary progressive MS, there's nothing we can do for you. I'll see you next year. Contact the MS nurses if you need to see me.' I walked away with that news. If it had been any other incurable disease I would have been... counselled?

Brian: Hell, talk to the nurse. Mine is a great help. She can't pull me out of the pit, but she can give me a lifeline to hang onto.

Wendy - MS nurse: I'm not here to defend neurologists. Some are brilliant, some... not so brilliant. I do wonder whether it may be that doctors are trained to make people better and they feel inadequate and a little bit scare when they can't. I know I do.

Chris: I feel for you, Hell. I was 'lucky' in that I got a whole 15 minutes with a consultant on Diagnosis Day. "Oh, and on your way out, you will find a leaflet stand, please help yourself to anything you think may be useful."

Simon - MS Trust: Research we've done has shown that the longer ago someone was diagnosed, the more they felt they were left unsupported by health services. What is clear is that people need to talk to the right people - specialist nurses and specialist neurologists. There's a map of specialist MS services at www.mstrust.org.uk/maps. It might help to try and see someone mentioned here. Not everyone will be suitable for everyone, but at least it makes sense to talk to someone for whom MS is a specialist subject.

Chris: Thanks for that link. By the way, I have also discovered another really awesome website (and why isn't this disseminated by GPs and neurologists? Gaaah) - www.dlf.org.uk. It's the Disability Living Foundation's site and well worth a visit.

Simon - MS Trust: Thanks Chris. The DLF site has a great deal of useful information on equipment. There is also Assist UK, a network of local groups who provide information about products and equipment for easier living and usually have 'showrooms' where people can try things out. These are also listed on our map of services at www.mstrust.org.uk/information/services/.

Wendy - MS nurse: If you could change one thing about your neurology appointments, what would it be?

Karen: I think we all know that there is no cure. Speaking for myself, I would just like to feel like I hadn't been thrown on the scrap heap. I have been left feeling very alone and frightened. I am also very bitter that I am now forced to give up on drugs that have completely transformed my life just because I have no money! Health just comes down to money every time.

HellMS: How wonderful to realise that it's not just me that feels ignored and left in the cold or overrating this awful feeling of neglect and indifference. 'Self manage' what a cop out. If you don't self manage does that make it your fault?

Wendy - MS nurse: I can't give you false hope about the drugs, but please don't feel that nobody cares. The MS Trust wouldn't have organized this chat room if there weren't thousands of people out there who do care.

Karen: I think this chatroom is great. It's nice to know I'm not alone in feeling the way I do.

Jane: I haven't found the neurologists' appointments much help either, apart from the first one. But the physios' advice has helped and the occupational therapist has definitely made a difference to my quality of life.

HellMS: One thing I'd change about my diagnosis day - take time and even pretend interest. It may have been all in a day's work for him, but for me it was a thundering blow. This is not just for Christmas this is forever! I have used the MS Trust helpline. Only there and here can I call it like it is.

Karen: My neurologist didn't actually even tell me I had MS. He told me I had 'an inflamed nervous system'. It was me who asked him if he meant MS! I had already worked it out for myself after being told to 'go away, it's all in your mind'.

Chris: If I could change one thing about the appointments, I'd ask for it to be a 'team' appointment, with a neurologist, an immunologist, a virologist, a geneticist, and a bacteriologist. MS IS NOT A NEUROLOGICAL DISEASE! Except in its manifestation... Throw the debate open to ALL the medical sciences, take it out of the jealous grasp of the neurology department.

Wendy - MS nurse: Interesting point, Chris. The neurologist team would definitely help diagnosis, but I'm not so sure about the long term management. Wouldn't you prefer a physio, nurse, occupational therapist etc?

Chris: Wendy, let me give you a laugh (the hollow variety...) These are the agencies/ professionals dealing with me currently: GP, neurologist, MS nurse, occupational therapists, physiotherapists, social services, Re-ablement, Time for Life, MS Society Support (charity), Upstream (charity), Care Direct, plus others that have slipped my mind.

Of these, apart from the GP and MS nurse, the most effective have been the charities. Of the remainder, no one seems to talk to anyone else, with the result that nothing gets done.

Chris F: Have to say I agree with the general trend of this chatroom, ie neurologists and the medical profession sidelining cases if they reach primary progressive stage. My neurologist discharged me when I refused to have the lumbar puncture, after already being diagnosed and asking 'how is this going to

help ME?' I've not seen a neurologist for about six years now, and just visit my GP (who agrees about the neurologist) when things get too difficult.

I think the profession needs to spend some of its time looking at helping those with primary progressive MS, as well as the very worthy task of trying to support and assist those with other forms.

Wendy - MS nurse: I agree, I always learn far more from my patients than any text book.

Tim: Good morning all. Interesting watching the comments here. Does anyone else feel that MS service in their area is in two tiers? Relapsing/remitting MS people get a far quicker response and get to see physios etc far more easily than people with primary progressive MS? Is that because they are on expensive disease modifying drugs where the drug company money is?

Wendy - MS nurse: I don't know about other areas, but in mine the drug companies don't fund the physios etc, so it makes no difference to the referral times. When people start on disease modifying drugs they usually have regular blood tests to make sure the drugs are not causing any problems. This means that they are generally seen more frequently.

Chris F: Call me a cynic, but I do suspect that Tim has a point about the drug companies interests being prevalent, and neurologists time perhaps somewhat biased accordingly.

Wendy - MS nurse: I agree drug companies are pretty powerful as they command huge budgets. However, we would be stuck without them as they also have huge research funds. It is in their interest as well as ours to find a cure and effective treatments.

Tim: I know several people with relapsing/remitting MS who get seen regularly by an MS nurse and physio. Their symptoms are no worse than mine, mobility certainly better. I had to wait months to see physio for one half hour session.

Wendy - MS nurse: Have you asked for more regular contact from your MS nurses? Even if it is not face to face, but by phone?

Kerry the Shrek: I have primary progressive MS, diagnosed in 2000. I'm still working full time in an engineering company. I went to see my neurologist once or twice every year. I've rarely seen an MS nurse. It seemed seeing the neurologist was waste of time, because they say that I have primary progressive MS and no treatment is available for primary progressive MS. I tried an un-prescription called LDN, as advised by a colleague, and it seems to help, but not much. The neurologist only wants to see me to see how I cope with MS when it worsens from time to time. I do get frustration sometimes with no better medication like other types of MS.

Wendy - MS nurse: I do worry when people say that they have been told no treatment is available. No cure is currently available, but most symptoms can be helped to some extent.

Chris F: Yes, after discharge from my neurologist, nothing else has been offered. I did contact the MS Nurse, but was told I'd need a referral from the neurologist! As he'd sort of blown his top at my query and refusal, I stopped there! I do occasionally pay for a massage at my nearest MS Therapy Centre (Huntingdon).

Chris: Oh I would recommend the MS Therapy Centres to everyone - they are one bright spark of practical hands on, useful intervention. I go to mine weekly for oxygen treatment (helps with fatigue), and the attitude of the people that run them and work at them are a model that the NHS should study very closely.

Simon - MS Trust: MS Therapy Centres are also included in the map of MS services at www.mstrust.org.uk/information/services/. MS nurses are on here too.

Wendy - MS nurse: Chris F, why don't you ask your GP to refer you to a rehabilitation consultant instead?

Chris F: I'll try that and ask about a rehab consultant. I should say that my GP suggested the alternative of going to London to see a different neurologist (apparently there is a twinning arrangement with the LHA) but I just didn't feel up to travel on the train, underground, etc.

Roger: I have secondary progressive MS, but since my diagnosis my neurologist, doctor, MS nurse, LAMS Day group and local MS branch have given me nothing but excellent support. I am just glad to live in Norfolk!

Sheila: The MS service in Tayside in Scotland is excellent - special thanks to neurologist Dr O'Riordan and all MS nurses there.

Jane: One thing I think could be given more emphasis is that it is a grief process. The previous me has died - the one who had a job, could drive, go out when I wanted to, had hobbies, be reliable, didn't have to deal with a variety of symptoms etc, etc. A couple of years ago I was given a place on a pilot of a programme that is now called Emotional Logic. (www.emotionallogiccentre.org.uk). This has helped me better understand the anger, frustration. It does not eliminate it, but I don't waste so much time going round the same emotional circuit. It teaches that emotions have a useful purpose and we can learn to harness rather than lose the energy taken up by emotions.

Wendy - MS nurse: I totally agree, the diagnosis of MS is like a bereavement. I will be checking that link when I have finished this chat room. Thanks.

Sylvia: I have been taking low dose naltrexone (LDN) privately since March. I was diagnosed in December 07. I really can tell the difference when I don't take it - more fatigue, can hardly walk at all etc. Why can't the doctors and neurologist acknowledge that it is worth prescribing it on the NHS if the patient does see some improvement? Why should I have to pay, when the drug is cheap to produce?

Kerry the Shrek: That true. Once I felt fatigued, tired, bit weaker etc without understanding why. When I took LDN in the evening before bedtime I realised that I had missed taking it for two days. It seems LDN must be working. The NHS

should provide this. I had it for two years already. At £27 per month, it's cost me £648 so far!

Chris: The failure to trial LDN is a classic example of what is wrong in the system. It has ALREADY been tested at full dosage for use with drug addicts (to replace methadone), but apparently no-one is willing to invest the money required to test a low dose version for a 'minority' use. The farce is that there really is no need to test a drug at low dosage that has already been approved at ten times the dose for other patients. Yet until it is trialled, GPs have no remit to prescribe it.

Simon - MS Trust: The good news on the LDN front is that proper trials are beginning to take place (some results were presented at the recent World Congress meeting in Montreal). Having some scientific evidence can only help this debate. The LDN work seems to have been mostly looking at safety issues with help with symptoms a secondary aspect, but it's a start.

Jinty: I have recently made contact with a GP in Glasgow who is going to see me re LDN. My GP contacted three neurologists who were unwilling to give her the OK to prescribe it. Yet this doctor in Glasgow is doing so! A question of cost?

Kate: Can LDN be taken with other MS medications? I assume LDN is for symptoms rather than disease control?

Simon - MS Trust: Because LDN stimulates the immune system, it should not be taken by people also taking one of the beta interferon drugs or other drugs that suppress the immune system. The full strength drug should not be used in conjunction with an opioid-containing medication or with people with hepatitis or liver problems. I haven't seen whether the recent safety trials of LDN in MS have looked at these issues with the low dose version.

Wendy - MS nurse: Most medications have interactions with other drugs to some extent. As long as your doctors know you are on it, any contraindications will be flagged up. I think the MS Trust have a factsheet on it.

Chris: The low dosage of LDN is VERY low - somewhere between 2 and 4mg, compared to the 30mg or so used to replace methadone. I tried it once but I couldn't tolerate the interference to my sleep patterns and the constipation it caused.

Simon - MS Trust: Thanks Wendy, yes we do have an LDN factsheet.

HellMS: I asked if I could try Sativex for six months. The MS nurse told me no consultant would sign for this. I could however go to a private GP and try Sativex, let me guess - all at my expense! I don't care if the evidence is anecdotal or placebo (regarding trials), they can do nothing else for me so why not let me try it. I'd know if it worked or not.

Wendy - MS nurse: I have had patients get Sativex from an NHS GP, after applying to the PCT for funding. Information for GPs is available from the manufacturer, GW Pharmaceuticals. I would ask, what symptoms do you think are not being controlled adequately by conventional drugs, that you feel you need to try Sativex?

Simon - MS Trust: Provision of Sativex varies. As it is prescribed on a named patient basis - ie the individual doctor agrees it is relevant for the individual patient (the doctor is responsible if anything goes wrong) - provision varies widely. However, we have heard of people who have had the drug funded by their PCT. We have a Sativex factsheet if that helps you discuss this with your GP.

Kate: My diagnosis fluctuates between relapsing/remitting MS and secondary progressive MS. My main problem is with walking, although I have episodes when I can walk quite well with crutches.

My question relates to spasms. They have got worse recently with my legs feeling frozen stiff in the morning. This morning I had the sensation similar to when you want to stretch and it felt like a spasm ran down my front to my legs. I try and keep my legs at 90 degrees and thus any spasm will push them into the bed rather than letting them go violently straight.

My knee joints are agony a lot of the time so I rely on a wheelchair (wrong I know) rather than trying to walk. I take Baclofen but don't think it works. Any advice?

Chris: I'm using gabapentin for spasms (which to me are the worst effect of MS). It seems to work quite well, though it does have the effect of 'deadening' the limbs so that they feel heavier and less responsive. Your GP should be able to prescribe gabapentin, it's a regular drug.

I also find that keeping my legs cool helps to prevent spasms. I never wear socks and keep my trousers rolled up; warmth to the legs and feet is the worst trigger for me. Oh one other thing, Kate, I tried baclofen early on and found it awful. I tried amitriptyline afterwards, which was better, but gabapentin works best for me so far.

Kate: Thanks Chris. I always wear socks and ugg boots as my feet are always cold, so if heat causes spasms not sure what to do.

Vicki - MS nurse: Kate, what dose of baclofen are you currently on? Have you been given any exercise or positioning advice?

Kate: I take 15mg in the morning and 20 at night and my MS nurse suggested I take some if I wake up during the night to try and calm any spasms which may occur during the rest of my sleep time. I was taking another 15mg at lunch time but have stopped to allow me to take more during night. Bit erratic I know.

I did try Tizanidine 5mg which completely knocked me out and gave me a dry mouth. Perhaps I should just take at night?

Wendy - MS nurse: If your knees hurt (assuming you haven't got a non MS problem such as arthritis) it could be that your thigh muscles are going into spasm or your walking posture has altered. Ideally, get a physio to assess you - easier said than done in some areas. Also, there are a lot of newer drugs for spasm now. Speak to your GP or neurologist. Don't forget the excellent publications available from the MS Trust and MS Society for further advice.

Kate: I really need to sort this as when I wake, the first thing I think of is 'are my legs stiff...do I need the loo...will I be able to get there?' I always can, but I still stress. I am particularly tired at the moment too.

Wendy - MS nurse: One of the problems is that most drugs are relatively short acting and even if you take them last thing at night, they don't help first thing in the morning. Personally, I don't advise taking drugs during the night, just in case you are very tired and forget how many you have taken. My consultant prescribes clonazepam at night for similar problems. It is worth asking your GP.

Chris: Given the choice between cold feet and spasms, I go for cold feet! (I'm used to it now...).

Kate: I tried clonazepam and again was knocked out the next day. To be honest the spasms have got worse since I have tried to strengthen my thigh muscles. I use a static bike and can now feel my muscles twitching around my knees at the bottom of thighs. Could this be why my knees are sore? I do have problems with my patella and have seen relevant consultants but something is aggravating them.

I moved to a new area in January. I have only seen my community physio once as, if I have an appointment that clashes or she is ill, she then has no availability for weeks, so don't know who to ask.

Chris, if my feet get cold my legs and feet ache and throb.

Vicki - MS nurse: At night do you have a pillow to keep your knees slightly apart and a little raised? Or are you lying flat? Positioning during the night can affect how your legs feel in the morning. As Wendy has said a review of your medications might be useful.

Kate: I sleep on my side with a pillow between knees but when I wake, I am frozen stiff.

Vicki - MS nurse: The bike may well be influential here. If you want to continue, make sure you are in the ergonomically correct position. As a cyclist I know just how important that is and what it does to the knees if you are not! Has anyone advised you on this?

Kate: No one has advised. I currently sit on my chair with an Oxycycle [a passive exercise machine] in front or an active one, although I've given that a break now.

Jane: I'd go for cold feet rather than spasms. I find my feet get hot at night and then spasms start. I was recently told about a yoga breathing technique 'sitali' cooling breathe and tried that a couple of nights ago when hot feet woke me. I went back to sleep instead of enduring spasms until I'm so awake I get up. You'll have to ask a yoga teacher how to do it, but it was really simple, if it was that that helped.

Another thing I use at night to put my feet on when hot is a chillow - 'The cooling water is contained in a polythene pillow so it doesn't feel damp. The lower surface is fleeced to stop it slipping about, but the upper surface is shiny plastic. You can slip it inside a pillow case on top of your normal pillow (it is only about 2cm thick) or you can lie directly on it for maximum effect.' You can get them from www.soo-cool.co.uk, a site run by someone with MS.

Wendy - MS nurse: Kate, if you have problems with spasm, stretching rather than strengthening often helps. Thigh stretches are relatively easy to do and can be performed on a bed if balance and standing are a problem.

Kate: To stretch my thighs I can only do at night. I find lying on my front and bringing my heel to my bottom the best. In the morning this would be impossible. I am fine standing. How do you suggest I strengthen though?

Vicki - MS nurse: It might be worth getting an assessment of your seating/positioning and exercise regime, and you may need to do a different type of exercise to address leg spasms. Also a review of medication. It is a horrible symptom that needs to be sorted out for you.

Chris: Why not talk to your GP about trying gabapentin instead? Then if it doesn't work, well at least you tried it...

I use one of those Niagara massage pads every day, and they help with my spasms too. Trouble is, they are fiendishly expensive. I got mine second-hand, I was lucky.

Kate: I'll speak to my physio on Monday, but it could be posture etc. I'll also ask my MS nurse to see if I can try gabapentin. Thanks.

Ali: I have secondary progressive MS. I'm taking part in the CUPID trial (Cannabinoid use in Progressive Inflammatory Disease). However, I am left feeling very low. I don't know if this depression is due to the cannabis, or a result of the MS, or just my life circumstances. Don't seem to be able to find anything to go on for - and I do feel really guilty as I know I'm lucky to be taking part in the trial. Don't expect any answers from you - just thought I'd write. I do not want to be withdrawn from the trial as it's the only possible hope that's been given to me.

Wendy - MS nurse: Sorry to hear that you are feeling so low. Please seek help from someone. There are lots of symptoms of MS that we can't do much about but depression isn't one of them (with the right support). I appreciate you don't want to come off the trial, but if the drug is causing you to feel worse, it would be for your own safety. Anyway, you may be on the placebo and it is nothing to do with the drug.

Jinty: I live in the Western Isles of Scotland. I couldn't agree more with all that's been said about being left on your own to make the best of things. I have secondary progressive MS. The Health Board out here has recently appointed an MS Coordinator to audit the incidence of MS in the Western Isles. I recently had a multi agency meeting with this co-ordinator - neurologist, physio and the coordinator - which was really useful. My worry is what's going to be available for us when the three year funding is finished?

When I had my annual review, my neurologist in Glasgow told me there was nothing more he could do for me other that rehabilitative care. The feeling of abandonment is very frustrating!

My legs are slowly getting worse. I now have a FES on my right leg, which is wonderful and allows me to walk short distances with two sticks.

Gail: I've found rehab a better option that the neurologist - more practical advice. It may feel like abandonment but perhaps this is a better option.

Vicki - MS nurse: If the MS Coordinator is successful after three years of what we call 'pump prime' funding, the likelihood is that the post will continue with what they call 'pick up' funding. People who use the service can lobby their health boards to keep the service if it is really helpful. That is important.

Karen: I have had FES since 1999. Wonderful, but something else I have to pay for myself.

Alun: I have FES via Salisbury Hospital. It's first rate and has kept me walking!

Chris: I don't know what FES is, but if it is that little electrical box that means you have electrical implants into your legs, then Mus-Mate does the same job, but with no electricity and no implants.

Karen: No implants, just electrodes stuck to the skin.

Simon - MS Trust: There's info on FES (functional electrical stimulation) in another of our factsheets.

Chris: I must just make a plug for Mus-Mate, a device developed down here in the south west by the husband of someone with MS. It is a shoulder harness from which bungee straps are suspended - they attach to your footwear and lift your feet up when you walk. It is a VERY simple idea, and has had the European kite-mark approval for medical devices.

The little walking I can now do is thanks only to the Mus-Mate I'm wearing. I'd recommend it to anyone who finds it difficult to walk, which means everyone with MS! Their website is at www.musmate.co.uk.

Jane: Will endorse Chris's plug for Mus-mate, as it helps me.

Alun: I have secondary progressive MS diagnosed in 2000. I was a very active sportsman. Now all that is gone, but I will not adopt a 'no one cares - there is no way out' attitude. I still help a local carers charity, secretary of the local rugby club, broadcast on local radio and am a governor of two schools. Pain is a constant 'friend' but I won't give in! Support from my GP, neurology consultants, OTs and MS nurse is excellent. We are not forgotten, but just feel it.

Any advice on acupuncture as an alternative therapy? Also any advice on pain in one limb (left arm). It looks like alabaster some days - poor circulation I guess.

Wendy - MS nurse: Difficult to advise on the pain via a chatroom. Is it definitely MS? Not due to your previous sporting activities. What is the pain like?

Vicki - MS nurse: As Wendy says it is hard to advise on pain without a full history. Does the acupuncture help?

Alun: The pain is dull numbness with occasional spasms of shooting pain. It's not due to an old sporting injury, it is the MS. I go to acupuncture twice if not three times a week. The Acupuncture is with needles and electronic pads (very like the FES electrodes stuck to the leg). I feel a little better afterwards - my physio noticed I could do my torture exercises better after a morning with my Chinese friends.

Vicki - MS nurse: Glad to hear that acupuncture has some positive effect. There is some serious research into traditional Chinese medicine, including acupuncture, to try and understand what works (and doesn't work) and introduce it into conventional western medicine.

Jinty: Like Alun, I was a very active person. Skier, hill walker, badminton player - in fact all types of sport. And as I taught geography, I used to take pupils away on active field trips. I also agree with you that people do care and that it is just a feeling of abandonment, simply because there seems to be lots out there for relapsing/remitting MS and not a lot for secondary progressive MS. I try to keep as active as possible and swim each week. I am also on the CHP (Community Health Partnerships) here and am still involved with the Parent Council at the school. One thing I am not doing is sitting around feeling sorry for myself!

Vicki - MS nurse: Thank you for making such an important point. Our feelings and our thoughts can sometimes influence how we behave and how we see the world. It is right to be sad and angry about having any form of MS. It is right to be open to the many ways of dealing with it, and to be hopeful of treatments. But it is very hard going if someone is filled with negative thoughts and feelings all the time, as well as trying to live life with MS.

Alun: Quite right Jinty, 'never give up, never give in' is a phrase I repeat to myself and anyone who will listen to me. No magic pill yet but be around when they find one!

Jinty: Thank you for that. Most of the time I am very positive about my life and don't let MS dictate what I can and can't do. I have recently been prescribed pregabalin 75mg to take twice a day. I take one at about 8-9am but am unsure when I should take the other one. Any advice, please?

Vicki - MS nurse: Is it for pain?

Jinty: No, it's to relieve the sensation of extreme heat in my back.

Vicki - MS nurse: I would try taking the second dose at about 6 to 7pm. See if that keeps you comfortable. If it doesn't, try slowly changing the time according to when you feel symptoms. For example, if you aren't able to get through the night but have had a reasonable day, you could take it later in the evening. If you are getting really uncomfortable by teatime you could take it a little earlier.

Jinty: Thanks for that, Vicki, I shall try that. I was prescribed 5mg diazepam for spasms and find that that is very effective. I also take amantadine for fatigue, which I also find helpful. I should have said I take the diazepam once in the morning and one at night.

Vicki - MS nurse: Diazepam can be very useful for spasm, particularly at night. Although it is used with caution it is very effective.

Denise: Everyone thinks I'm managing so well - happy, funny, working, getting on with life. However, we're on the verge of bankruptcy. My husband cares too much for me and took his eye off the ball in business, our new grandchild is very ill, planning another daughter's wedding without funds - shall I go on? I can't

take much more and just want out. There is nothing at the end of a long difficult horrible tunnel except more black. Why me?

Vicki - MS nurse: I am so sorry that it is such a tough time for you, and for the family too. Is the black tunnel about these other issues as well as the MS, or do you think the MS is the cause of all these other problems? Have you spoken to anyone about this Denise?

Jim: Sorry to hear your troubles, Denise. MS can mess up so much more than one's health.

Wendy - MS nurse: Thank you for taking the first step to getting help. It can be very difficult to admit when you are not well. What a wonderful way to get into debt 'husband cares too much for me'. Make an appointment to see the Citizens Advice Bureau or a debt counsellor. Don't blame yourself - many businesses fail. I know it may sound flippant, but think about it. You have a loving husband, a daughter planning a wedding and a new grandchild (even though he/she is ill). Please go to your doctor and get some professional help. Stop pretending everything is all right when it isn't. It isn't a sign of weakness to have emotional problems. I would be very surprised if your family and friends haven't noticed there is a problem anyway. Let the people who obviously love you help. Take care.

Denise: I honestly DO try to be positive. I even succeed most of the time. But I can't pretend to myself can I? I've even been on a recent trial at the National for the sodium type thingy [lamotrigine]. No change, although I did have a day out with hubby before we became too poor! I can be honest on this occasion as I've got a smile on my face and everyone else assumes I'm happily working as usual (contradiction in terms there for a start)! Looked into FES but nowhere here and I don't think I'll get the funding anyway.

Wendy - MS nurse: Have you heard of 'mindfulness'? Put very simply it's all about making the most of the here and now rather than worrying about the past or future. Some areas have courses but you usually need a GP referral. If not, borrow a book from the library. It can be very effective for some people.

Denise: Hubby's taken all the right steps and now set up IVA [Individual Voluntary Arrangement] to sort out debts - we're beginning to miss the daily phone calls from creditors (see, warped sense of humour again, can't help it). Definitely feel MS has affected my life - and that of my family. Otherwise I could go out there after all the cheap deals, trawl charity shops, help in looking after the grandchildren, use public transport, have family and close friends over for a jolly dinner, etc. etc. Get the picture?

I don't think of the past as it's gone, and I cope with the future as it becomes necessary. I only read books by the likes of Jackie Collins and John Grisham. So, you see, I really am a lost cause, deep in the recesses of my mind! I do keep trying to be positive - nobody's interested if you're not and I know there's no point - but there's always something that rears up to knock me down. The latest is the sick granddaughter (eight weeks old with congenital heart defects. My daughter thinks she's not responding, and I agree but haven't said this to her).

Jane: Denise, I've found Emotional Logic www.emotionallogiccentre.org.uk helpful. They have a self help activity pack for around £6. It is easier than a book and has seven cards that help you see what you emotions are doing. EL is based on the work of Elizabeth Kubler-Ross. I gave one to a friend who was going

through a series of events and she reported to me that after using it for the first time she had a much better night's sleep.

Denise: Thanks. One thing I can do - and always have been able to - and that's sleep. Obviously it's what keeps me going and gives me something to look forward to every morning when I rise. I will look into Emotional Logic stuff!

Nessie: It was interesting to read how others are feeling. I was diagnosed in October last year with primary progressive MS. but was also unsure if I had secondary progressive MS showing relapses on top of my other symptoms. I have a weak leg and after years of orthopaedic appointments was referred to a neurologist. I can't thank my physio enough as they always said I had something else wrong with me.

My consultant has been excellent in all the information but does say there is nothing YET out there for me. Nurses are available if I need them and my own GP I can't thank enough for the help he has given me over the past five months. I had a bad do after some steroid treatment, which knocked me for six. Back on the road to recovery and back to work, although only part-time at the moment.

I was always someone who worked at a fast speed but I'm having to slow down. Yes it does get me down, but I realise I'm not alone out there. I just keep reminding myself my electrics aren't working properly and I need 50p for my meter. Keep your chin up everyone, there's always someone out there who you can turn too if you look.

Jinty: Hi Nessie, glad to hear you are recovering. Like you I can't praise enough all the people who help me out here. I have wonderful GPs, neurophysio and physios, OTs, MS Coordinator. It would be nice if there were more multi agency meetings with MS sufferers as the one I attended was extremely beneficial.

Vicki - MS nurse: That is a very good analogy that you have given us. The electrics don't function as well as they should when someone has MS. Delighted to hear that you are being supported in managing your condition, and especially to hear that you are returning gradually to things. Lots of people try to go at everything full on as before, find they can't, and get despondent. Being kind to yourself and pacing it is a very good thing. Often a gentler, more considered way will allow for much more success for people with MS.

Nessie: Yes I am lucky. I have had a lot of help as there is a rehab hospital which does a lot of work for all sorts of conditions as well as having in-patients. I even attend a MS fitness programme for eight weeks run by a physio who specialised and worked with people with MS. What a hoot that was as there were only three of us.

It has been a difficult year and more so the last few months. I have twin granddaughters who keep me going and some very very good friends. Not forgetting a vey understanding husband (who actually took the news worse than me).

Interesting thought - my niece also has MS. She has had hers since her early twenties, lives in Canada and has gradually worsened over the years. Her favourite expression is 'my feet are dancing without me'. My problem was getting it later on in life. I've always been awkward!

Sometimes humour is the only thing that keeps me going - making myself laugh when probably I want to cry. This all started with problems with my leg and knee - I had a floppy leg, hence the visits to orthopaedics. I kept falling over - even though I don't drink. Sometimes I think I should so that I could use that as an excuse too.

Denise: Nessie, hi! Like your style - sounds like we're on the same wavelength. Grandchildren are wonderful aren't they - especially so when you can give in to everything and then send them home! Trust me on this, a drink (or two or three), can be quite jolly at times (as long as you have an accessible loo nearby, and thereby hangs another dilemma!). Keep 'em laughing and you sometimes even forget about real life.

Nessie: Going back to some of the comments others have made about primary progressive MS, mine has also been a general decline over quite a few years, which has been the hardest thing to come too terms with. But I'm not going to let it get the better of me. I only ever say that I've had a set back and I'm not going to give in to it. People look at you amazed when you say what is wrong as in some cases it can be the invisible condition people suffer with. We're probably all the same people underneath and haven't changed - just in the way we do things. Not as good a day as usual today and typing might be a bit erratic. Who would have thought I used to be a secretary many years ago?

My little ladies (my twin granddaughters) gave come to visit so I'm going to sign off for a while but I will sign back in later on. Thanks to all. I've enjoyed reading all the comments and replies and it has made me realise I am not on my own in how I feel with primary progressive MS and that is quite acceptable to feel like that. Also that there is always help and a shoulder to cry on out there!

Jane: Could you please explain the difference between spasm and spasticity? I read something somewhere recently that made me think doctors/nurses use the terms differently to me. I now regard spasm as the uncontrolled movement and spasticity as the stiffness after the movement. Before I called both spasms.

Chris: I think you are right Jane - it took me a long time to realise that when they said 'spasticity' they meant general MS stiffness. I can live with that. It's the spasms that are so awful especially as you can feel them coming and know they are about to occur.

Wendy - MS nurse: Jane, you are right. I find it easier to think of spasticity as general stiffness. Spasm tends to be intermittent, such as your legs shooting out / pain / cramp etc.

Vicki - MS nurse: You have got it spot on! Spasticity is the abnormally increased tone in muscles that make a limb feel very stiff. We all need a degree of this tone to enable us to stand. Spasm arise out of spasticity and happens when a stimulus (which may be a whole range of things) causes the muscle, or whole limb or part of the body to move involuntarily and uncontrollably. They are horrible symptoms but we can do a lot to relieve them.

Simon - MS Trust: We had an article on spasticity and spasms in the last issue of our Open Door newsletter.

Rob: I am not too sure what classification I come under. I was diagnosed 12 years ago and told I was relatively benign. Since then it has been a slow, gradual deterioration with no relapses or remissions, but I feel much weaker and unsteady on my feet now. Surely this must be primary progressive MS? What is the difference that defines secondary progressive?

Chris: I'm told that secondary is what develops after relapsing/remitting. Primary progressive MS is something that starts from nowhere and just gets worse. Usually it starts later in life too, relapsing/remitting MS is a 'younger' disease, though you can never generalise too much.

Rob: I was diagnosed in my mid 40s. Do people progress from primary progressive MS to secondary?

Simon - MS Trust: Echoing Rob's question, we have had several comments sent in in advance that asked how you distinguish what is progression - particularly for people who seem to be moving from the relapsing form of MS.

Wendy - MS nurse: Secondary progressive MS occurs after relapsing/remitting MS. It is when you get sustained deterioration, independent of relapses, which continues for more than six months. Primary progressive MS tends to have a gradual deterioration from onset, without relapses and remissions. Older people (40+) tend to get it and unlike relapsing/remitting MS, it is just as common in men.

Kate: In some ways I hate the categories/types of MS because some cases are neither black nor white. This obviously makes the medication prescribed tricky as its really only for the type of medication that you are put in one of the MS boxes.

Simon - MS Trust: Yes, it can be very difficult to try and assign labels to people with MS. The different types are not always easily distinguished.

Rob: Thanks for that, but can you clarify more about if after 12 years of slow progression from the outset with no remissions ever whether there is a likelihood of having 'progressed' to secondary, (particularly when recently fresh limbs are starting to show mild symptoms) or is it basically irrelevant?

Simon - MS Trust: In general terms, progression is progression - primary and secondary just describe the journey to get there (eg was there a period of relapses before the progression or not).

Wendy - MS nurse: Secondary progressive MS occurs after a number of years in people who initially have had relapsing/remitting MS. I know the word 'progressive' can sound gloomy, but it's basically about not having good and bad days and your condition being more predictable. Remember, that as well as MS, general aging is happening to us all and this may be contributing to your symptoms.

Rob: I know I am not taking this in too well but I understand what you mean about progression being progression. But a gradual slide downwards over so long a period with NO relapses points towards still being primary progressive MS?

Simon - MS Trust: Can't say in a specific case, but in general terms that does sound like the definition of primary progressive MS.

Chris: Rob, I think you have got confused. Secondary is not the stage after primary at all. Secondary refers to the stage after relapsing/remitting. People

with primary progressive NEVER go to secondary, and the two forms of progressive are - I understand - very similar.

Simon - MS Trust: Chris, Thanks, a better use of words perhaps.

Rob: Thank you all for you answers. Yes it seems I was confused about the stages not following each other and that helps me a lot mentally to know the true facts. And yes, I'm getting older - now being an ancient mid-50s - so maybe I shouldn't expect too much lol.

Chris: Let's hear no more about the mid-50s, Rob - that's where I am! And you know what they say, men peak physically at 19, mentally at 60... lol.

Bill: I'm very much a fen when it comes to physical peaks :).

Jinty: I have real problems with my balance. What can I do to try to improve this? I try to do some exercises when am in the swimming pool but would like to try anything else. I was wondering if Pilates might help.

Vicki - MS nurse: Pilates, the Alexander technique, and even yoga will all help with balance. I would also second Wendy's earlier point about mindfulness and would recommend that anyone with MS considers setting aside time for this exercise.

Jinty: I have spoken to a teacher of Pilates and she suggested that exercising on a Swiss ball would probably be helpful. With my balance I would probably spend more time off the ball than on it! But everything is worth a go.

Bill: My physio says that with balance you have to keep challenging the balance to build up any benefit. The imbalance seems to be doing pretty well, but I'm creeping up on it.

Wendy - MS nurse: If balance is a problem, don't exercise using the ball unless you are being supervised. With Pilates, you can improve your core stability just as easily with lying down exercises.

Jinty: I will see if I can get the teacher to give me some Pilates exercises to do instead of the ball, thanks.

Steve: Hello, This may be a stupid question and not relevant, but what is the role of an MS nurse? Nobody has ever explained it.

Wendy - MS nurse: Not a stupid question at all! What does an MS nurse do? We aim to provide advice, support and information for people living with MS in our catchment areas. Individual areas vary, but most offer telephone consultations, nurse led clinics and occasionally home visits. Oh, and chatrooms.

Chris: Has anyone here tried the triple-antibiotic treatment? This is based on the suspicion that MS is triggered by the Chlamydia bacteria? Everything has failed and I am seriously thinking of trying this, but I would like to hear from someone else who also tried it if I possibly can. (My own symptoms began - coincidentally

or not - shortly after I had a bacterial infection on my nose 10 years ago, so the connection interests me greatly).

Wendy - MS nurse: Our neurologists haven't prescribed the triple antibiotics for anyone. Mainly because not everyone with MS is found to have Chlamydia, so something else must be going on as well.

Chris: The neurologists are unlikely to have anything to do with the antibiotic theory as it runs counter to their own specialty. Turkeys don't vote for Christmas. What I'm more interested to know is if anyone here has tried this and if so, what effect did they find?

Wendy - MS nurse: I know it may seem like some neurologists are out to score points, but in my experience they just want to help people with neurological conditions. Our's are always willing to refer people to other centres if trials aren't being conducted at our own.

Richard65: I was diagnosed in 1979 and the following year was told by the consultant I was in remission. I remained in remission until 2-3 years ago when MS raised itself with fury affecting balance and mobility along with speech. A neurologist at Barts confirmed post tests/CAT that MS had returned and was unlikely to remit. Unfortunately I have been left there as there seems to be no treatment for this stage and I am having to rely on analgesic therapy, which I balance with my asthma drugs - joys of side effects. Surely there is more I can do? Although exercise is exhausting...I try. I really do not know what I can do or try - any help?

Wendy - MS nurse: Exercise does not have to be exhausting. I encourage people to perform stretching, toning, range of movement exercises if fatigue is a problem. Also Pilates and yoga can be performed lying down if mobility and balance are an issue. Never exercise to the point that you are too exhausted to enjoy the rest of your day. Little and often is often the answer.

Richard65: Fatigue is a major problem - at home and at work. I need to look into Pilates and yoga. My biggest problem is me. I think I should be doing as much as before, but am so fatigued I can only manage a pathetic effort - silly I know....but that's me...

Wendy - MS nurse: Never underestimate how disabling fatigue can be. If you try and fight it, the fatigue will probably win. Much better to pace yourself, listen to your body and rest when you need to. Personally I think it is better to rest for half an hour and enjoy the next few, rather than struggling through your day. Quality not quantity is an old but valid saying. There are lots of self help books from the MS Trust and MS Society with useful practical advice.

Simon - MS Trust: Last year the MS Trust produced a book called Living With Fatigue, written by an MS occupational therapist, which contains much useful information.

Karen: Richard, Wendy is right. You have to learn to listen to your body. Don't even try to overdo things as you will suffer for it. Just do what you can, if and when you can.

Denise: Forget before - it's gone and is no more and won't return. If you have ever suffered true fatigue (and not the tiredness my daughters get after a few

late nights) you know there is no quick fix pick-me-up potion. It's not a question of giving in but one of giving up to your body's need for sleep. There is no need for pathetic effort - accept the inevitable and return refreshed after!

Richard65: Aye! I know what you are saying is right - just the ol' stubborn workaholic trying to maintain control.

Jinty: I wondered if the heavy feeling I get in my right hand and arm as the day progresses is fatigue?

Wendy - MS nurse: The heavy feeling you describe is probably the muscles in your hand and arm fatiguing , perhaps due to weakness, rather than general fatigue. Try and make sure your arm is well supported when you sit or lie down. Sometimes cooling it can help. If it is severe, medication could be an option. If it is not your dominant arm, it may be more comfortable in a sling during the evenings.

Elsee: Is there a relapsing progressive MS?

Wendy - MS nurse: Good question. I would say yes, although it is very rare and not universally recognised. I have a few patients who have primary progressive MS and who do seem to have definite relapses not attributed to anything else such as infection. The difference is that they don't get the usual good recovery in between which is characteristic of relapsing/remitting MS.

Elsee: I have difficulty speaking but have now noticed I also have difficulty in bringing air up through my throat and I'm feeling breathless. My throat feels tight in the lower throat / voice box area. I've noticed I'm yawning a lot. My speech and language therapist has suggested practice yawns. Is this normal/common? What can be done?

Wendy - MS nurse: What is your posture like? Do you tend to slouch forward with your head down? Breathing difficulties are not common in MS. Don't automatically assume it is MS. Get it checked out, if you haven't done so already.

Elsee: The speech therapist who is treating my speech problem hasn't said it's not MS.

Wendy - MS nurse: I would still see your GP to rule out a potentially treatable cause.

Simon - MS Trust: As mentioned earlier, the MS Trust is at the start of the process of working on a book about progressive MS. If anyone has any thoughts on what they would like us to include and what would be useful, please contact us on info@mstrust.org.uk. Similarly, please let us know if you'd like to help us when we get to the review stage of the book. Thanks.

Elizabeth: I already know about alternative and complementary therapies - tailored exercise plan, antioxidants, vitamins, etc, and my mother has maintained

good overall health despite MS. Is there anything new on the horizon in alternative/complementary therapies?

Wendy - MS nurse: Glad to hear that your mother has kept well. I haven't heard of anything particularly new on the alternative/complimentary therapy side, but there are several trials underway for 'conventional' medicine. I don't want to comment specifically on each as they are still in the trial phases and the results

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Elizabeth: Do people with MS still get plasmaphoresis?

Wendy - MS nurse: Not routinely. We have used it on occasions in the past for people with very aggressive MS that is not responding to other treatments. Also for people who can't tolerate steroids etc for other medical reasons. It tends to be limited for people with other autoimmune diseases, such as Guillain-Barre and myasthenia gravis where it has been found to be more effective.

Elizabeth: Do people with primary progressive MS get IVIg and if so, what are they given?

Wendy - MS nurse: Again, in similar situations to plasmapheresis. Although not routinely for primary progressive MS, but for severe relapses. It can be very difficult to obtain in some trusts.

Elizabeth: What about stem cell therapy for myelin repair? If someone has progressed to the point of having axon damage, will stem cell or other therapy still work?

Wendy - MS nurse: Stem cell therapy holds great hope for the future, but it is in its early stages. There are still lots of problems to do with targeting the areas that are damaged etc. Also, as we don't fully understand yet what causes MS, where do we target? Myelin, oligodendrocytes or precursor cells? As I said, stem cells hold great hope for the future, but not just yet.

Simon - MS Trust: The MS Trust also has a factsheet on this.

One of the first stem cell studies to involve humans is currently taking place in Bristol. A very small study (only six participants) and only looking at safety issues at the moment, but a first step perhaps.

Irene: I have heard of people being in 'end stage MS'. Is this a stage in primary progressive MS, and if so, how does it manifest itself?

Wendy - MS nurse: End stage MS is really another way of saying advanced MS. People with both primary progressive MS and secondary progressive MS can reach this stage. It normally refers to people who have acquired complex disabilities as a result of their MS. Treatment is very much aimed at controlling symptoms that may develop.

Irene: When they say 'end' do they mean terminal? I am concerned about the speed of my deterioration, is their anything I can do to help myself?

Wendy - MS nurse: Difficult to say. It would probably be fairer to say that people are no longer responding to treatments and unlikely to make a good recovery. Unlike illnesses such as cancer, it is very difficult to predict when someone with MS is likely to die, unless they have secondary complications and other medical conditions. I helped care for a lovely man recently who had 'end stage MS' for 8 years.

Irene: What are secondary complications?

Wendy - MS nurse: Secondary complications are things like infections and pressure sores that anybody with severe disabilities can be prone to getting - although good care greatly reduces their likelihood. If you are worried about the speed of your progression, ask your GP for a referral to a rehabilitation consultant. They can help you make the most of what function you have now and in the future. They work closely with physios etc and it is often another way of accessing these services.

Irene: Thank you Wendy, it's useful to know what these terms mean.

Alison - MS rehab nurse: hello Irene, what form is your deterioration taking?

Irene: My main problems at present are very limited walking, unsteady gait, neuropathy, breakthrough muscle tremors and spasms, weakness in my hands and arms, and altered sensation in my hands. I also have a supra-pubic catheter.

I have just been diagnosed with type 2 diabetes and have oral medication to try and control it. Due to my bowel problems I have been advised that a colostomy may be my best solution. I am also being investigated for breathlessness - apparently not usual to MS - and am awaiting tests, an echocardiogram and thallium scan.

Is there anything I can do to help myself?

Alison - MS rehab nurse: A second problem like diabetes can often upset MS for a little while. It is good that you are now on medication to stabilise it. Do you have a rehabilitation consultant?

Irene: Would a rehabilitation consultant be helpful?

Alison - MS rehab nurse: When many things are troubling you at once, like you say they are, a rehabilitation consultant can co-ordinate management options. It's important not to try and do too much at once else we don't know what's helpful and what isn't. I think you would find this approach helpful.

Deb: I have been am an MS sufferer since 1986. I think I am moving into secondary progressive. I have a couple of questions. Question one is: Do MS patients have low blood pressure? Question two: Is there connection between fluid on the legs and the heart? My doctor says it's my age and prescribed me surgical stockings. Water tablets were mentioned. I'm only 47. That's not old, is it? :-)).

Alan - MS nurse: I hope 47 is not old as I will be that this year too!

Low blood pressure is not an issue particular to MS - it can sometimes be associated with reduced mobility though.

As for fluid on the legs - again this can be due to a combination of factors including reduced mobility, cardiac history, and sometimes a poorer lower leg circulation that is a feature of some people's MS.

Alison - MS rehab nurse: What makes you think you are moving into secondary progressive? Fluid on the legs can be the result of deterioration in mobility. What is your mobility like?

Deb: I just hope there is no other illness lurking!

Jill: 47 is no age for swollen legs and ankles. It can happen through reduced mobility - which may be associated with MS - but as a person with secondary progressive MS and a tendency for swollen ankles, I'd say that your GP ought to check you heart before prescribing water tablets. I have regular foot massage to try to avoid swelling. It's great therapy and very relaxing. Pampering is especially good for us I feel :-).

Deb: I have no cardiac history but I do have lower leg sensitivity and water retention.

Alan - MS nurse: Unless you are very breathless on minimal exertion, I hope you wont worry too much about heart disease at your age - especially since it doesn't look like that's the case from your reply! Simple things like elevating your legs while you are resting, regularly and gently exercising your ankles, feet and knees, and yes, possibly wearing compression stocking to reduce risks and improve the return of blood / fluid from your lower legs, might be all you need. Perhaps discuss this more with your GP or local MS team (if you have one).

Jane: I find the regular use of a chi exercise machine helps swollen ankles. I found one with variable speeds so could do a very gentle session as well. I think it is something to do with the type of motor as not all chi machines are the same. It is done for up to 15 minutes lying down! So was also relaxing once I got used to it. I got mine through www.surgeofchi.com and had a month's trial first. It seems to give other benefits like pain reduction. Not everyone will fine it useful and there are some contraindications when the exerciser should not be used.

Kate: Can I suggest for swollen ankles The Circulation Booster from High Tech Health. They allow a 30 day trial and as I'm a real sceptic I then asked for an extra month. It is a big TENS machine.

Deb: Alison, the problem is a stiff ankle. Walking long distances can be hard going. Have not had relapses for quite some time. I still don't like using a stick. I'm being well looked after, I just don't like being put in to a pigeon hole before my time. Getting back to the question about swollen ankles, there is a reason for it, isn't there. I don't like getting fobbed off with "it's your age".

Alison - MS rehab nurse: Starting to use a stick can be difficult for many people. Have you thought of buying one that folds up and goes in your handbag? Then its there if you really need it. Another lady I know uses ornate sticks as a fashion accessory. Has anyone assessed your stiff ankle?

Kate: I am annoyed with myself that when I was diagnosed I did not start exercising more. I never did really before diagnosis, instead being a career girl staying at work till all hours. As a result I've gone from walking with one stick to two crutches and a wheelchair (although I have dislocated both knees since diagnosis which put me back).

Can I ask how I can increase strength without increasing spasms? Has anyone tried Power Plates? I tried swimming in a hydro pool but the heat knocked me out.

Alison - MS rehab nurse: Have you seen a neuro physiotherapist? They are the experts at providing exercises that maintains strength without increasing stiffness or spasms.

Alan - MS nurse: We now recommend some form of exercise for every one of our patients - and it doesn't have to involve running a marathon. It can be simple things you can do from a chair or on bed (or on the floor if life has taken you there today...).

Chris: I would like to offer the things that I have found helpful in ten years of primary progressive MS:

Early stages
- Exercise (aerobic - most important: MS is not muscular, the muscles need tone, you need fitness)
- A folding bike (in the boot of my car, for when distances beat my legs)
- Acupuncture

All stages
- MS nurse
- MS Therapy Centre
- Mus-Mate walking aid
- Mental stimulation (even sudoku)
- Frequent rest (under my own terms)
- Vitamin D (high dose) plus zinc (high dose) plus Co-Q-10 (high dose)
- Vitamin B complex and vitamin E and multi-minerals
- Massage pad (or regular massage)
- Tai chi and/or yoga and/or meditation for relaxation
- HBO (oxygen therapy)
- Movi-col (there is nothing else to conquer severe constipation, it's a miracle cure)
- A urine bottle (for the car)
- Shopmobility (for when nothing else will do)
- Diet (universals: eliminate caffeine and stimulants, cut right down on alcohol, don't smoke; a diet high in vegetables, protein such as poultry and fish, complex carbs like rice, oats, mung dahl, etc: and when the neurologist tells you that diet is totally ineffective and will make no difference, smile sweetly then go off and find out for yourself that the truth is different)
- Your hobbies, interests, and a sense of humour
- Laughter
- The kindness of strangers
- Becoming your own MS expert (no-one knows as much as you do about your condition, and you will find that out many times over).

Alan - MS nurse: I think you should write a book on your experiences - or at the very least contribute to the next MS Trust update of their excellent Tips for Living with MS.

Chris: I would Alan, but I never heard of it until now! (Why don't GPs hand out these links?) Anyway, if you let me have the details of how to, I will happy to contribute to it.

Simon - MS Trust: A reprint of Tips for Living with MS is due out before the end of the year and we are always looking for new ideas. Post them to us or email info@mstrust.org.uk

Nessie: Like your list Chris. I've only been officially diagnosed a year but had mobility problems for five or six prior to that. I agree with them all and if at all possible trying to keep a sense of humour helps. I just tell people that my electricity is running out and I need 50p for the meter, or I've had a power cut. If nothing else it takes the edge of the condition and certainly makes people smile.

I have primary progressive MS which has slowly deteriorated over the years. Self management with pain killers and exercise see me through. I have been told by my consultant that because of what I have there isn't a lot of treatment out there for me to try that would be of any benefit. I have had two courses of steroids - one helped my weakness in my leg, one didn't. I do experience period of pain and discomfort so tend to take my painkillers on an as and when required basis - probably not the best way forward but I don't want to get reliant on them just yet. I visited a physio and have done an MS fitness programme run by our local physio tem (if there is a programme like this in your area it is well worth going on). You get to meet people like yourself and I had a real good time. So I suppose really I'm just learning to treat it the best way that fits me, and most of the time for me it works. My GPs and MS nurse team are always there if I need them too.

Jill: I am resisting taking medications for fatigue - modafinil, gabapentin. What do others feel about these drugs?

Alan - MS nurse: I wouldn't say gabapentin was a first line choice for fatigue. Iit can cause a fair old bit of drowsiness as a side effect, so can make fatigue worse initially. Modafinil is often a second line treatment where amantadine has been unsuccessful - or where the pattern of fatigue is more like narcolepsy (where you suddenly drop off thru the day unexpectedly).

I would always recommend checking things like anaemia, low thyroid function or low vitamin B12 levels before considering medication. I would also recommend you find a good fatigue management programme running in your area if you can. (it may not be specific to MS but may well be highly beneficial).

Alison - MS rehab nurse: I agree with all Alan has said. If there isn't a fatigue management programme in your area you may be able to get one to one advice from an occupational therapist.

Simon - MS Trust: The MS Trust book Living With Fatigue may be of some help. Mention of the drugs but mostly looks at conserving energy and using it most effectively. It is written by an occupational therapist and is based on the fatigue management courses she has run.

Jill: Thanks for all the input. I think I manage my fatigue quite well really. Being very tired is a recent development and a trade off between taking baclofen for cramps at night and suffering the side effect from that. Thyroid function is definitely one to have looked at. I think I am also aware of a link between drinking alcohol and increased fatigue the next day :-(

Living with MS is so frustrating because it - well - it progresses - and when you think you have it sorted then another challenge makes itself very obvious.

Chris: I'm taking gabapentin for spasms, Jill. It seems quite helpful. More side effects than amitriptyline but more effective. Fewer side effects than baclofen and MUCH more effective.

Tess: I have just been diagnosed with primary progressive MS in the last couple of weeks. Like Roger earlier, I live in Norfolk and have had excellent support. Within three weeks of diagnosis from the consultant, who had time and was compassionate, I had been referred to and seen by my MS nurse, GP and physio. All of whom are offering ongoing support as, when and should I need it.

Alan - MS nurse: You are very fortunate to have a local and supportive team. In theory everyone with MS should have fairly local support from an MS specialist in their area. If you don't have that - ask your Health Authority why not!

Nessie: Tess, hi. I was diagnosed with primary progressive MS last year after having had problems with walking and a floppy leg that gave way. I live in Fleetwood near Blackpool and my consultant has been excellent. He took the time to explain everything even showing my all my scans and there is always the MS team at Preston Royal, whom I now come under, and my own GP to offer support. I have enjoyed this forum too as if you look back at the chat room you will see there are others like you out there and you are not alone. Keep smiling, that's what I say. Even when it's tough, tomorrow's another day.

Denise: Hello again, Nessie! Good times with your granddaughters? I was diagnosed 19 years ago but really had very little problems. Now in a wheelchair most of the time but always used to tell people it was the shrapnel causing my mobility problems (and no I'm not old enough to have been in the war - although I was there when it all happened in the 60s)!

Nessie: Yes I've had a good time with the girls. They stop with me and my hubby once a week. They tire and wear me out but always put a smile on my face and keep me going. Two little terrors of two and half going on... years, who are just learning to use a potty. All good fun.

Denise: Know exactly what you mean. Ours is two and two months - being potty trained (not at my house) and we have her every Friday. Joy of the week!

Alan - MS nurse: You have a great sense of humour and I firmly believe that a strong positive attitude helps people with MS to cope so much better with anything life or MS throws at them - well done you!

Alison - MS rehab nurse: Humour is a powerful ally.

Nessie: Thanks Alan. Sometimes it's the only way. I'm one of the type of people who never sits still and is always on the go. I work in with children in a school and have some very good friends. My boss didn't even know that I'd been having

problems getting about on my bad days when I limp. I just go to work and get on with it. Yes, sometimes I could sit and cry and have done and think why me. I don't do illness. What I say to everyone else out there is keep going and, if things go wrong, just think about it being a set back and try not to give in. That's what I'm trying to do.

Tess: Nessie, thanks for your support. I have and will continue to maintain my life in a positive way. I may have primary progressive MS but if it wants to be part of me then it is going to have to keep up or hang on for the ride :-) There is always an alternative way to get round things, sometimes you just need to think about it. Having fallen off my bike many times I keep threatening to get a tri-cycle, and while can still pedal it I will! On the plus side, when I fall over and wet myself now I can blame the MS and not the gin! ;-)

Nessie: That made me smile and giggle, Tess, especially the comment about the gin :-) I must admit when I tell people what I've got or if I'm having an off day, I say it gets on my nerves and now have an excuse for everything. Plus I can even say that I know I have a brain as I've seen proof. My consultant showed me my scan to explain everything to me. Not sure whether that was a good idea as I was never sure if I truly had one. Lol.

Tess: I too was surprised that they found a brain on my MRI scan. Like yours, my consultant took the time to go though the scan in detail with me, showing me where the scarring is etc..... I now do not refer to the white scars as scars. On the scan they looked bright and shiny so I now refer to them (as do my friends and family) as Tessa's brain diamonds :-) Sounds so much more exclusive and special don't you think? My friends have been fab (that's what makes them true friends) and many are now thinking about inventing all sorts of contraptions, should my legs give up completely, to get me from a to b, down the shops and of course onto the seafront to checkout the 'eye-candy' :-) I might have MS but I'm not blind! !

Chris: "I too was surprised that they found a brain on my MRI scan," Tess - thank you, that's the biggest laugh I've had all day!

Nessie: I like your comment about your 'diamonds'. I was lucky as I only had a few diamonds on my brain, which the consultant wasn't overly concerned about, but connected them to the others which are at the top of my neck. So all those years of bending over small tables and getting neck ache and back ache (I work as a nursery nurse, or teaching assistant as we are called now) was primary progressive MS. Good job I suppose that I eventually had a floppy leg which prompted ms after many years to get diagnosis started. Perhaps the lack of drink to go with the falls especially during the day had something to do with it.

Also my big toe does daft things and I can't stand my left foot being touched. It has a bad habit of jerking up when touched. Fascinating, but strange. My friends have all said that if I end up in a wheelchair they want to push me in it but only if they decorate it with pink streamers and balloons. I've suggested a pair of 'heelies' trainers with wheels in the bottom to get about but I probably wouldn't be able to stop and fall over.

Tess: Like you, I also have some diamonds in my neck, and it was only the stupid leg thing recently that prompted me to go to the doctor. I have apparently had the MS for eight years and am lucky, I know, as it seems to be a slow and steady progress rather than rapid. Chris - I'm glad I made you laugh :-) A smile is a ray of sunshine whatever the weather as it always makes you feel good :-).

Denise: I have a horrible discolouration on one leg (about a 50p piece sized circle) which has been on me for ages. No pain or feeling - could it be some kind of blood clot? There is a very small one on the other leg which does sort of go away at times.

Alan - MS nurse: I am a little concerned about your 50p piece sized mark on your leg. I can't see it or feel it so can't make a best guess. I would definitely recommend you to see your GP and if you remain concerned ask (or demand) a referral to a dermatologist. Sorry I can't be more specific, but these things you really need to see and touch.

Denise: You haven't answered correctly. I will not pass GO or collect £100 - in fact even my GP knows I won't see her unless there is a crisis (and this isn't yet). I don't get any pain and my ankles or always a little swollen with the accompanying fat feet (thank goodness for maxi dresses this year and forever after). Thanks anyway - maybe someone will take heed and sort it out for me!

Sheila: I have secondary progressive MS. I just wanted to share with you all a comment from my brother's blog, written in May this year. "I am a tetraplegic suffering from primary progressive MS and living in a care home. I can't dance anymore but I still hear the music."

He died a few weeks later, donating his brain to MS research.

He took part in many activities and was doing an Open University degree course until recently. He was trying to find a Spanish language course to join just a few weeks before his death. I hope we can all still hear the music.

Is there any research into familial tendencies? Mother and cousin also had MS.

Alison - MS rehab nurse: What an inspiration your brother must have been to those about him.

Alan - MS nurse: I am very sorry to hear about your brother and your loss. I have known too many people like him over the years, but it's definitely a reducing number as the years pass. People become more pro-active in their self care and own management, and of course when we have increasing advances in medicine it all helps.

Research re familial MS - yes there is a load of it. I was listening to Prof George Ebers last week who has just concluded a large study of the genetics of MS. This was carried out in Canada, although he is now based in England. There are of course recently discovered genes (or alleles on genes if we need to get technical - but lets not...) that determine a susceptibility to MS - but not yet linked directly to risk.

In families the risk of MS is still around 2-4% depending on who has the MS initially. So although we do obviously see runs of MS in certain families for a short time, it doesn't usually sustain as stronger genes from other families suppress these susceptible genes.

Where I live and work we have 1200 people with MS, but of those only around 12 families have more than one person with MS.

Hope that helps a little?

Sheila: Thanks for the info, Alan - very helpful.

Nessie: Interesting about how many people in your family have it. I have primary progressive MS and was only diagnosised last year probably having had it for years. My niece has it and she lives in Canada. Sam is in her 30's and has had it for possibly over ten years, gradually after relapses ending up in a wheelchair. Last I knew she was still being very independent as far as she can and lives in flat. I like your comment about the music as Sam would often say that her 'feet were dancing without her' when they started to shake. She is one incredible person as I'm sure your brother was. I do get asked if it is inherited and beginning to wonder how much truth there is in that statement. I wonder how many more there are out there like us, with close relatives with it.

Denise: When my daughter starting to get tingling pains and other associated aches she was referred to a neurologist who decided straight off she was 70% positive MS, but just to get a scan. This we did post haste but after much crying and guilt and very bad thoughts she was totally clear. The consultant's original letter stated "Mother in wheelchair with MS" - was that a benchmark for diagnosis? We tried to talk to her boyfriend and explain the future ahead but he was having none of it - they are now getting married in February and we've all put that particular nasty episode behind us for now.

David: Having looked through all the chatroom entries, my summary of the earlier ones would be that many people have not had an adequate service from either the neurologist or the MS nurses. I feel that this is a sad state of affairs, given the work that the MS Trust, MS Society and others have put into helping people with MS. As this seems a common thread, is it possible that something can be done about this over the next year or so?

Simon - MS Trust: It seems that the problem is getting to see the right people. In MS in general, but progressive MS in particular, input from a range of health professionals can make a big impact - physio, OT, nurse, rehab team, speech and language therapist, social workers and more. If people can get to see the right person - often the MS nurse - this can help to start joining the various services together. It's alarming when the initial links aren't made and people don't get the help they need and which is often out there.

Alison - MS rehab nurse: There is often help for people with MS via a rehabilitation consultant led service. Unfortunately many health professionals don't refer to rehab for progressive MS. This is a mistake as there is mush the service can offer.

Kate: I've got exercises and do all the Pilates/bed based ones. In an attempt to strengthen leg muscles I bought an exercise static bike which unfortunately has increased my spasms. To be honest I haven't found MS physios that great. Has anyone tried power plates or vibrogyms? They can vary in price but some people with MS think they are great.

Vicki - MS nurse: Some people with MS do like them but there is little research, as yet, to say for definite if they make a difference. Like many things, it is variable how people will react because each person's MS is unique.

Kate: Yes, that's what everyone says, but I keep hoping someone may say its worth getting one. The wide variety available makes it hard to decide.

Nessie: My consultant sent me to a neuro-physiotherapist as I have a problem with weakness in my left leg which can make walking difficult when it's tired. No fun when you've not even been drinking! I also invited to take part in an MS fitness programme run by a physio. Ask around as I can certainly recommend this course and certainly think it will help. Good luck in finding one and hope it will work for you.

Simon - MS Trust: As people are mentioning exercise, perhaps I can point out our book Exercises For People With MS and the DVD Move It For MS.

Jinty: Can anyone tell me about hyperbaric oxygen chambers and the theory behind what they can do for people with MS.

Vicki - MS nurse: There is something called the Cochrane Review which examines every bit of evidence for a health or treatment topic (whatever it may be) that is available and determines if it is proven to be of benefit. Unfortunately with hyperbaric oxygen they have found no evidence to support it. But some people with MS feel it helps. Why they should is not known.

Alan - MS nurse: Hyperbaric oxygen is used in a chamber similar to ones divers use to combat the bends when they come up too quickly from a dive. You breathe oxygen while sitting or lying in a pressurised room and gradually the pressure is reduced. I think the idea is that you will purify the oxygen supply to muscles affected by MS and remove toxins. In practice only some people report any improvement and in research studies done (I only know of two significant ones personally) the evidence for or against was conflicting. HBO is not supported by NICE guidelines on the management of MS due to lack of supporting evidence.

Also some places might rip you off! It's not well monitored, although IS provided in some MS therapy centres.

Brian: I think if you go to an MS Therapy Centre they will treat you properly. But as people say it doesn't work for everyone (what does?)

Chris: I have HBO (hyperbaric oxygen) therapy once a week. It is in no sense a cure of any kind, but it sure helps me with fatigue. It kinds of 'rejuvenates' the blood but I don't know the science behind it). If ever I'm tempted to think it is not doing anything, then a couple of weeks without it soon shows me the error of my ways!

Kate: Does anyone find that they are affected by stress? As soon as I'm stressed my feet feel glued to the floor. So I don't go out unless I've got the support of my partner, which is really depressing.

Alison - MS rehab nurse: Stress often affects MS symptoms for the worse. This is difficult to manage because de-stressing ourselves is a very hard thing to do. I hope knowing it is an often experienced problem may reduce your understandable anxiety about this impact on your mobility. There are ways of managing stress but they need to be learned when you are not rushed or stressed.

Kate: Thanks Alison, I just have always stressed even as a child so I'm not sure I'll ever control it.

Roger: Earlier Sheila mentioned MS occurring in families, but I have another puzzling story. When I was about two years old, my mother developed polio myelitis. She belonged to a small church group of about ten mothers. I have recently discovered that two and possibly three or more of these ten children now have MS. Surely there must be a connection with polio?

Denise: I was born in 1949 and vaguely remember the polio outbreak and all our infant school being vaccinated - but don't know what happened to anybody else. Surely any link would have been picked up by now though? Let's face it - nobody seems to know and the more they investigate the less they find out.

Roger: I was born in 1953 and my mother was one of the last people locally to get polio. Although I have had MS since I was 19, I was only diagnosed two years ago! One of the others was diagnosed about ten years ago and the other less than a year ago, so this 'anomaly' is only just appearing. No one apart from me and the others would make the connection after 50 years!

Nessie: It was fascinating to read your comment about MS in families. I am the youngest of four and it is my eldest sister who lives in Canada who has a daughter who has it. All her family was born out there. I visited her two years ago for another of her daughters wedding and met up with Sam for the first time. I had been having trouble with my back and leg and it was on my return from there that my physio started the ball rolling by saying that there was an underlying condition and wanted me to chase it up. After many arguments with orthopaedics - problems with back pain - and referrals to a neurologist I found out twelve months ago what was wrong. My MS has manifested itself in the mature time of my life - 40+. Who said life began at 40? It was fascinating how people's ears pricked up when you mention that MS is in the family. I was a very premature baby (born at 28 weeks) and have been different all my life. Perhaps one day I will go back to Canada and visit my family again, perhaps I should also let them know what I have too.

Frances: I was diagnosed in July 07 as secondary progressive MS and of course I want answers to the impossible question of how bad will it get? My balance is awful and my right leg sometimes sags and trips me up. Do you think physio would help and should I ask my GP to refer me?

Alison - MS rehab nurse: Your desire to know about your future is very understandable and it would be helpful if you could discuss this with someone. Do you have access to an MS nurse or a rehabilitation nurse? Physio may well help and also a splint to support your "sagging foot".

Frances: Yes I have access to an MS nurse but he is so busy.

Alison - MS rehab nurse: Many people are busy, but sometimes a little support at the right time goes a long way. Either contact your MS nurse (I am sure he would want you to) or else ask if there is a rehabilitation service you can access. Many people find rehab helpful at this point in time.

Vicki - MS nurse: It is always worth having a review for guidance and advice on the best exercises, the right posture, ways to move and relax so as to avoid problems from bad habits - something we are all at risk of, but more so in MS. You ask how bad will it get; and you are right to say that is an unknown, but often the MS goes into a more slow lane, almost as if I has 'burnt out' of the merry go round of relapse/remission. Investing in your physical health and well being is very important to help prevent extra complications.

Frances: I will contact the MS nurse tomorrow.

Vicki - MS nurse: I'm sure you will benefit from regular monitoring. Even if we are very busy, we would never want problems that could have been prevented getting out of hand because it was felt we were too busy, or overloaded.

Alan - MS nurse: I am also glad about Frances contacting her MS nurse soon - I rarely get annoyed with a single patient of mine - but when they come in a disaster saying "I didn't want to call you because you're so busy....." grrrrrrrr! I just so wish they had! Then I need to explain, as I usually do, that I am here to be busy FOR you. If I am busy, leave me a message and I will get back to you as soon as I can. I don't think I'm too different from any other MS nurse I know. So yes - contact us - even if you think its something minor or daft, we may be able to solve your problem or answer your question in a jiffy, but leave things to go on and on out of control, disaster looms (well maybe).

Frances W: I was diagnosed with type1 diabetes 35 years ago which is OK with my insulin pump. I was diagnosed with MS seven or eight years ago. I'm having problems with heavy legs etc at the moment but nobody can advise which of my conditions cause what! Have suffered with neuropathy in my hands for last four years and can't get over it.

Alan - MS nurse: I think irrelevant of which condition is causing your problem, you should be getting support to fix it (or at least improve things for you).

A good physio or neuro-physiotherapist should be able to accurately assess you and give you exercises, treatment or equipment that may help? If you don't know how to access this, try asking your GP or contact your Health Authority help desk - it should be in the phone book.

It could be, for example, that TENS will help your neuropathic pain without disrupting your diabetic control. Also if tripping is an issue a functional electrical stimulator may help retrain your tripping foot/feet to lift properly and safely. This needs specialist assessment in a clinic.

Frances W: I have bladder problems and my diabetic consultant is quite adamant its MS. My neurologist discharged me last year as no treatment available, so use fantastic Speedicaths. Have the MS nurse's phone number so might contact her.

Vicki - MS nurse: I would like to think you will have regular contact with your nurse so that she can keep a watch over you. We are about to launch new national guidelines for managing bladder and bowel issues in MS in November. These will help to guide everyone on the best possible practice.

Alan - MS nurse: Good plan, Frances! May be that ISC [intermittent self catheterisation] is the best plan for you if you have large residual volumes left in your bladder after emptying. Did you have bladder scans before starting? A proper check using urodynamic studies should be considered and possibly a continence physio could advise on biofeedback and pelvic floor exercises? It's certainly not all about medicine and tubes.

Frances W: I had the tests a few years ago and my local continence nurse turned me on to speedicaths.

Alan - MS nurse: Glad to hear that, Frances. Our continence nurses are my best pals up here! I would definitely rely on them to keep an eye on any changes with your bladder, as they are best placed to advise and alter treatments for your benefit.

Chris: Vicki, I'm glad you mentioned the Cochrane Review earlier. It is quite possibly the single most important thing anyone has mentioned. [Chris is in fact referring to the Coughlan judgement - see the glossary]

To put it in a nutshell: anything that is a 'medical need' is free under the NHS, anything that is a 'social need' is provided by the Social Services at your own expense. The Review proved that with Alzheimers (and by extension MS) the fact that someone has to come round and feed you and put you to bed is a medical need - it is directly the result of your illness and not simply old age or something like that.

Fight to be treated as health always! Never let them fob you off as a 'social case' without a fight...

Simon - MS Trust: Social care is a good example of unjoined up services. Social and health care are often seen as quite distinct entities (by those commissioning services), instead as part of the continuum of support for people with long-term conditions.

Vicki - MS nurse: Absolutely, a fundemental principle. We are all entitled to enjoy our fullest potential in health and wellbeing, and I hope that the divisions, both economically and socially, between the two will disappear! Florence Nightingale recognised they were interdependent!

Alison - MS rehab nurse: I agree with all comments about accessing joined up health and social care; it is so important to help reduce the impact of MS. If you are fighting for your care or services, don't forget the NSF [National Service Framework] for Long-Term Neurological conditions which has many requirements to quote.

Vicki - MS nurse: I agree with Alison. And don't forget, if you feel you are not certain about anything regarding your rights as a user of the NHS, go to your local PALS. There is also an advocacy service if you feel you are not able to fight your own corner very well. There is so much out there to help enjoy life and feel fulfilled. Contact the MS Trust anytime for info.

Jane: Where can I get more information about the health and social care as I don't understand what is being mentioned in the exchanges? Last year I had a sudden relapse affecting speech and coordination. A GP visited and night sitters were put in for six nights and then handed to social services and an agency. It took a few months for me to realise I needed some rehab input. OT now working with me, but seems I need to be better prepared.

Alan - MS nurse: There are good booklets available free from the MS Society on getting the best from health services and social services (also Scottish specific versions).

Simon - MS Trust: Alison's mention of the National Service Framework for long-term conditions is timely. This and NICE's guidelines for managing MS should be acting as a benchmark for the development of services. Research by the Royal College of Physicians and the MS Trust suggests that despite pockets of excellence, implementation of these documents by PCTs and commissioners is patchy at best and rehabilitation services are particularly poorly served. We will continue to press for the these blueprints to be followed and will run another review of services in a couple of years time. We'd also encourage users of services to question their local health authorities about how they intend to meet their commitments as regards these documents. You can read more about the 2008 review on our website. (In these days of devolved health services, these apply to England only).

Alison - MS rehab nurse: Services for emergency home support vary from area to area. Sounds like your GP put in intermediate care until social services could pick your care needs up. One of the aims of rehabilitation is to help people become better prepared (always with the hope that they may not need it). Ask your GP for referral to a consultant led rehabilitation service.

Vicki - MS nurse: We are also about to launch a commissioning guideline to make sure those people within the NHS who purchase services for people with MS know exactly what they should be buying on their behalf. Slowly things are changing and hopefully improve the daily living with MS.

Alan - MS nurse: I have to say the MS Trust and MS Society are doing a fabulous job is highlighting the need for as well as the requirements within health and social services! I don't know where we would be now without them!

Frances W: Vicki, good news re guidelines.

Jane: I think I fell through all the gaps in the system. Perhaps the proposed MS Trust book Simon mentioned earlier in the day can include something about the challenges faced by those with no family, thus no carer? Paid carers are not the same.

Alan - MS nurse: It's a great pity that some areas have not just gaps but gaping great canyons.

Simon - MS Trust: Jane, the Neurological Alliance (an umbrella group for charities from a number of conditions) has also produced a book called Getting The Best From Neurological Services. You can download it from the Living With MS pages of our website.

Alison - MS rehab nurse: I feel sad every time I hear about someone falling through gaps in the system. If you have no access to a specialist services

(neurology or neuro-rehab depending on what is in your area) please ask you GP for a referral.

Alan - MS nurse: In our service we have people attend the neuro-rehab unit and ward from three outlying health boards simply because they don't have a decent service. People with MS and their families seem really keen to travel a great distance to access a centre of excellence, however I do wish they would bang the drum for more local service provision in their own centre of excellence - that would be ideal.

Alison - MS rehab nurse: How I agree with you! There is a huge deficit in neuro-rehabilitation services. We must all bang the drum.

Jane: There are good services but for some reason, some things were not getting picked up. They probably would have been if I had a family carer who could have dealt with it. Sometimes it seems I just run out of energy to hold together all the things I have to ask for. That's why I'm suggesting some mentioned is made of the situation of those without family. The OT is now working with me.

Alan - MS nurse: I agree, life is always tougher when you live alone - whether by choice or by accident of life. It means you need to be more self-reliant and independent. Unfortunately, as you like others have found, MS can knock your independence out from under you and you suddenly need support from others - but who and how and where from are sometimes seemingly impossible questions.

I don't think its ever a bad idea for people with MS to plan ahead for all eventualities. Find out while you are well and independent who, how and where from. I know some people think it's a bit pessimistic when I say that to them, but you know, its like having 999 on your phone - you may never need it, but if you ever do.....

Roger: Nessie mentioned sensitive feet earlier. The bottoms of my feet have become very sensitive over the last few years. I thought it was just old age! Perhaps it's connected to MS instead. My wife blames most of my symptoms on old age.

Alison - MS rehab nurse: Your sensitive feet may well be MS related, and if that is so there is treatment available. So please go and see your GP and discuss treatment or referral to a specialist.

Vicki - MS nurse: This altered and painful sensation could well be MS related and there is much that may help. Ask your GP and/or speak to your specialist.

Tess: Spooky, I too have mega sensitive feet and toes which jerk all over the place when touched quite uncontrollably. That's jerk uncontrollably not touched uncontrollably (I should be so lucky!) This always posed a challenged to the beautician when I had a pedicure. I also have a small tattoo on my foot and when I had that done it took two of us holding my foot in a half-nelson to prevent the tattooist from scribbling all over my foot! !

Nessie: Its quite bizarre. My consultant says its primeval and shouldn't happen! Doesn't do it all the time though, but sometimes it will dance without me. You don't say how old 'old age' is but I just refer to mine as my party trick and having a foot that does strange things. But then again, I've always been different and awkward and my hubby will certainly agree with that.

Tess, your comment about your tattoo is interesting. That was something I said I would have done some years ago and have never got round to it. Can you imagine if like you I'd had one done and ended up giving Phil our local tattooist a black eye because I'd kicked him. Who would have believed me if I'd said it was not my fault! Still not had a tattoo done!

Alan - MS nurse: I have to say I've had a few laughs with my friends wondering what nursing will be like in 10-20 years time when all our lovely old wrinklies have the most weird and wonderful tattoos! I like the idea of some old dear having 'wipe here' (with an arrow) as you change her pad!

David: I have a neuropathic pain, at the top (back) of my left thigh and base of my buttock. No medication touches it, nor have four spinal injections over the last three years. I only get it when sitting or laying down, not when standing or walking. Does anyone recognise any similar symptoms, or can anyone recommend any treatments. My only hope seems to be a drastic visit to a neurosurgeon, to see if he can cut the nerve.

Vicki - MS nurse: A pain triggered by certain posture/position could possibly be a nerve root problem. Contact your GP to discuss a review of the symptom amd the best route forward. A physio or OT could look at your sitting and lying posture and what chairs/mattress/ pillows you use. An MS specialist of a pain clinic could look at medications and if anything helps at night. Are you sure this is MS related? It could be a mechanical problem, such as sciatica. A GP, physio and/or orthopaedics specialist could look into this.

Patricia: Is it inevitable that after years of using an indwelling urethral catheter, bladder cancer develops?

Alan - MS nurse: It is not inevitable that one will develop bladder cancer after years of having an indwelling catheter. I can't say I have seen any cases of this in my 27 years of nursing. I certainly can't recall any research articles describing this either - but would need to do an online search to confirm this as a true statement of fact.

Alison - MS rehab nurse: It is neither inevitable nor likely. Indeed I am not aware of any significant link. However, if there has been some change in the way her catheter or bladder is behaving; you should first see your GP and ask whether referral to a consultant urologist is indicated.

Jane: Perhaps the book can also include managing cognitive loss due to MS.

Alan - MS nurse: Cognitive problems can be assessed by an occupational therapy team, and by psychology services if they are more alarming. There are a range of things that can be advised to help minimise the worsening of cognitive deterioration and can improve some level of it too. This needs proper assessment to recommend the correct approaches for you and your family / carers.

Alison - MS rehab nurse: Both neurology and neuro-rehab services would be able to provide some information about cognitive loss and its management. You

seemed to imply earlier that if you had a family member things would not have been missed. In your earlier posting you mentioned cognitive problems. Perhaps you could get more out of health and social professionals when you see them if you took a list of things you wished to discuss - your OT could help. As a professional I like people to bring a list it ensures we discuss what is important to them not just what I ask about.

Alan - MS nurse: I agree. I often ask patients to make a list, because a mixture of memory problems or poor attention span added to fatigue can result in a lot of you guys with MS having memories as bad as - or worse than - my old befuddled brain.

I always make my own list of things people are telling me, otherwise from my end I will get brain drain and forget things too. So action points on my list will come from bullet points on yours. And I'd rather you told me all the things that affect your symptoms or problems than just hear the one or two things you can remember that day. So, yes, make a list and try to remember to bring it with you.

Jane: Yes I do take lists. I think the some of the problems go back to what was said earlier about neurologist appointments. But about the last relapse a family member would have spotted and said what I couldn't. The OT is helping now, and hopefully the situation will be better covered in the future.

Gina: I vary between relishing my independence and not being reliant on someone else, and complete fear that my condition will deteriorate so much that I have no one to help me and I'll end up in a home.

Alan - MS nurse: Just you hold on tight to that independence of yours! The minute it starts to slip - get in touch with your local service / MS nurse, because in 2008 we can do things to improve you, but it helps if we get in there quickly.

Alison - MS rehab nurse: We all enjoy independence, but remember, if the day comes that you need help, that help is there and should be provided as and when you need it. Although some people with MS do go into a home to be cared for, compared with the number of people with MS, this is very rare indeed. Remember we all need help sometimes, don't miss out on things because it would involve having help - you are worth it.

Gina: The forward planning thing sounds sensible. There's a lot of stuff that says live for the day, and it's right to some extent. No good living your life to conditions that haven't happened yet. But you do get the 3am cold sweat fears of what happens when I can't do x. Spending some time to put safety nets in place in the hope you never need them might be a reassurance.

Alan - MS nurse: It definitely does pay to plan ahead. It doesn't mean you will cover any or every eventuality, but if you have a list of contacts eg MS nurse, neurologist, social work department, physio, OT, dietician, speech therapist etc, then either you can call or ask someone to call them on your behalf.

Another area for those who do have family carers might be details of contacts for respite services. It may not even be out of the way extraordinary for some people to visit respite centres in advance of needing them, so they can see their options before a crisis hits. Of course, again you may never need that service.

Alison - MS rehab nurse: Yes, it's about getting the balance right - planning for more than one future. But knowledge of availability of help is comforting even though it may never be needed. Finding out what can be done and choosing what's right for you can help with those 3am cold sweats.

Nessie: Just reading the comments on putting in plans for the inevitable and worrying about what might be instead of enjoying what is here and now is a difficult one to overcome sometimes. In my own case I'd had problems with a floppy leg and was sent to orthopaedics. I had an arthroscopy on my knee to be told there was nothing wrong. Fine, I thought, but carried on falling and experiencing the same problems. I went back to orthopaedics to be referred to a physio, whom I can't thank enough. Without her pushing me to get seen by my specialist I wouldn't have got me where I am today. Needless to say the operation hadn't been needed but, hey, I got there in the end. So to all out there, physios are wonderful people and everyone else that goes hand in hand with this condition we all have to help us to have a good quality of life. So if this is what needs to be done, then we do it and enjoy what is certainly a new challenge to leading life in a different lane. Even if it isn't in the fast lane like it used to be and just moved down to the middle lane of life. I've enjoyed the chat room today and has certainly made me realise I'm not alone!

Jane: Fortunately planning for the future does not stop the enjoyments of today. If I'd realised sooner what was happening to me I could have had a better safety net in place.

Alan - MS nurse: I think Jane hit the nail on the head! Go ahead and make plans and build safety nets. Once they are there, just go out and have a ball! Even if you have to throw it instead of kick it.

Ferelith: My own experience of MS is slow progression and I am curious to know how far the disease can go. Is it possible that eventually it will affect my breathing? So far it is entirely affecting my physical mobility.

Tess: Good question from Ferelith, the same thing has crossed my mind too.

Alan - MS nurse: Breathing problems directly associated with MS are fairly uncommon. Most of the central organs such as heart, lungs, liver etc are not directly involved in MS. Sometimes the intercostal muscles - the ones between your ribs - may be weak and it's harder to fully expand your chest, but most people compensate for that by using their diaphragm.

In people very restricted by MS who are mainly in bed and have very limited movement, and more so with swallowing difficulties, thee is a higher risk of chest infections which severely affect your breathing - so very much worst case scenarios there.

Slowly progressing MS where it is mainly problems from the waist down, often tend to stabilise out over the years, and it's unusual to suddenly spiral out of control. You should have plenty time to plan out and enjoy a good (if restricted) enjoyable life. As I have stated previously though , make plans for the future for better and worse, and also contact your MS service if there are changes. Rehab services are not only for the 'well' and certainly not only for those with relapsing/remitting MS. They are just as important for secondary progressive MS and primary progressive MS.

Alison - MS rehab nurse: It is extremely rare to see breathing affected by MS, and only then when someone has been affected to the degree that they have very complex disability. Cough can be affected with less disability but this can be managed by help from a respiratory physio. Slow progression tends to stay slow progression so hopefully there are no unpleasant surprises in store for you.

Elizabeth: What current studies of treatments for progressive MS are underway? I'm looking for something concrete that works. I suppose that there is room for individual response to medications and therapies, but is there a pattern of treatment people with primary progressive MS are finding effective?

Alan - MS nurse: The CUPID trial is a multi-centre phase III trial looking at the use of a cannabinoid drug as a slower of progression in MS. It was shown in the CAMS trial [a previous study of cannabis based medicine] a few years a go that a follow-on group had slower build up of disability than those on a placebo medicine. So this trial is to look at that effect.

Other emerging therapies from trials include Campath - which is already available in some trial centres in England. New results have shown a 71% reduction in disability and 91% reduction in relapse rates. Not sure yet who this would be licensed for and whether it will benefit people with secondary progressive MS.

Elizabeth: My interest is more primary than secondary. Not aware of anything for primary progressive MS. Earlier I spoke to Wendy about plasmaphoresis and IVIg.

Alan - MS nurse: The CUPID trial is for both primary progressive MS and secondary progressive MS. I have just come back from the joint European & American Committee on Treatment & Research in MS conference in Montreal - and to be honest the bulk of the work is still very much focussed on relapsing/remitting MS and early treatment. However, there was some interesting early work on stem cell use - but nothing firmly conclusive as yet and still in animal trials on the whole.

IVIg is a bit controversial but is offered in some places as is plasmaphoresis. We use mitoxantrone in our centre for people who have a very rapidly progressing illness and it certainly slows things down quite dramatically and can even halt progression of disability in some. It's a chemotherapy drug though so has consequences in use. The MS Trust has a mitoxantrone factsheet.

Alison - MS rehab nurse: Elizabeth, you are asking interesting questions about studies. Of course, all people with MS are interested. I am a little worried though when this is always the main focus. There are scientists and medics working on everyone's behalf looking into something to arrest MS progression. My concern is that it is easily possible to become focussed on this and not on accessing what is already available in terms of managing symptoms and minimising disability by healthy living and being as active as you can. I do hope you are getting on with life and having some fun in the way many of the other people in the chatroom today are.

Elizabeth: True, Alison, but one hopes for the magic bullet.

Alan - MS nurse: There is work being done by Professor Chris Linington and his team in Aberdeen looking at an antibody called neurofascin which seems to be strongly involved with the destruction of myelin - and it comes from close to the

nerve body itself. Work is being done on an anti-neurofascin antibody which may well be able to halt the damage (a big theory and I may have got it a bit mixed up in simplifying it!)

Alison - MS rehab nurse: Since I've been in the room no one has mentioned a consultant led rehabilitation team. Does anyone in the room have access to such a service?

Alan - MS nurse: I work in one Alison - does that count?

Gina: I've not. Can you explain what they do and how you get in contact?

Alison - MS rehab nurse: A neuro-rehabilitation consultant and team provide ongoing access to assessment and management (drugs and therapy) of symptoms and the wider impact of having MS. The aim is work along with the patient to minimise the impact of the condition as much as those symptoms, disability, available services and environment allow. Liaising with whatever other services can help that person. Wow - there's an advertisement for you!

Nessie: Well here goes, its time to go to bingo. I'd like to thank Alan, Alison, Vicki, Simon and anyone else from the forum and to all those who have taken part today. I've found it very interesting and it's answered questions I've had in my mind and has certainly made me realise that - no I'm not loosing the plot. Good luck to everyone out there!

Alan - MS nurse: Glad we could help - and you got a lot more form the others with MS too - the real experts!

Sarah: Why is it that there are drugs for relapsing/remitting MS but nothing equivalent for primary progressive MS? Why do the relapsing/remitting MS drugs not work?

Alan - MS nurse: The main feature of relapsing/remitting MS is the inflammatory flare-ups caused by the immune response attacks. This is not a significant feature of primary progressive MS and is lessened in those moving from relapsing/remitting MS through to secondary progressive MS. The treatments are 'easier' as the process is more manageable.

Janet: I've had primary progressive MS for 13 years and I'm in a wheelchair. I'd heard that vibration trainers (like Vibrogym) helped people with MS and have just bought one. Have you any idea if it will help?

Alan - MS nurse: I think the main response is that obviously there has been no structured research in MS to show whether these help - but perhaps you could try them under supervision of an expert - in your rehab centre, perhaps, or with a physio - just in case they don't do you good? For example if you were to find they knocked out your central balance, that could affect the way you sit in a wheelchair or potentially affect your transferring. So not all gadgets that do good, do good for everybody. Don't try them on your own is my main suggestion.

Janet: I notice Sativex was mentioned earlier. I had the opportunity to go on a European trial of theirs last month. I am on the Best Bet Diet and was concerned that there might be wheat residues in their product as they use grain alcohol. They never answered my emails so I tried to do my own research. I found they use tartrazine in their placebo, among other e-numbers, so decided against the trial. They still didn't get back to me and I am kind of curious if there is any wheat/gluten residue in it. Any ideas?

Simon - MS Trust: Chris was talking about diet earlier as something that had helped him. Not the Best Bet Diet in his case I think. How have you found it has helped you? Have you noticed benefits?

Janet: Benefits of the Best Bet Diet? I am amazed. I've been on it a year and a half and so many of my symptoms have just gone. First to lift was brain fog, which was down to wheat exclusion. And it just keeps getting better.

Kate: Do you have to follow the diet down to the last detail? I bought the book and it looks exhausting.

Alan - MS nurse: Another thought on the matter - diets which are totally exclusive always make me raise my eyebrows. Everything in moderation is my adage in life (well maybe not everything). I would be concerned that you would consider not going for what could be a beneficial treatment because it may contain a very minute trace of a wheat product. Unless you have an allergy to wheat, should it really be that great a concern? Just a thought...

Janet: I do have a wheat allergy anyway. It was the e-numbers that cinched it for me. I want to get better, not worse!

Alan - MS nurse: Ah, well with a wheat allergy that's fair enough. We prescribe Sativex at our centre, but not sure about wheat content, and unable to find out tonight I don't think, sorry.

Janet: Kate, I didn't know there was a book. What's it called? Maybe Amazon have it. It does seem exhausting to start with but I excluded things one by one so I knew what it was doing for me and that way it was easier, just took longer.

Vicki - MS nurse: Just a final comment re diet. There is some evidence to suggest that a diet high in the right fatty acids may have some significance, but remember life is to be enjoyed. More work is going on with vitamin D as well, but none of these things change permanent nerve scarring and lost nerve tissue which is irretrievable loss. Often reducing wheat from the diet will help because we are not naturally designed to eat bread. Sometime getting back to what humans were designed eat - roots, fruits, little meat, nuts - can make us feel better.

Alan - MS nurse: just had a look on the GW Pharma site (the manufacturer) and there's no mention I can see of production process.

Janet: I live in Northern Spain, having abandoned the UK six years ago. Is there anything I'm missing from the NHS? Has it changed? Where are the best sources of new info on the Web?

Alan - MS nurse: Of course you are now missing the number of MS specialists available on the NHS to help all people with MS.

Best principal sources of information are the MS Trust and MS Society websites.

Vicki - MS nurse: The main change in the NHS (there have been many non productive ones) is something called the Darzi review. This sets out how clinical staff and patients will have more say on to run things, rather than managers. In theory.

People with MS can now access the disease modifying treatments if suitable without post code lottery. We shall soon see independent budgets for people who need long-term input, and scrapping of many of the prescription charges.

Alison - MS rehab nurse: That's a tough question, Janet, as I don't know what services your receive in Spain. I believe services are slowly improving. NICE guidelines and the NSF for Long-Term Conditions are helping.

Simon - MS Trust: For info I'd naturally suggest the MS Trust and the MS Society - if nothing else for the research sections of both sites. The US National MS Society supports a lot of research and the news part of their site might be worth keeping an eye on.

On the alternative side of things, where the guide tends to be what people use rather than research (as there is little in this area), the MS Resource Centre - www.msrc.co.uk - is very open to possible approaches, and, from America www.ms-cam.org.

Alan - MS nurse: Jooly's Joint is a great MS chat forum. You will get lots of support there.

Simon - MS Trust: Time to wrap things up. Thanks to Alan, Alison and Vicki and to Wendy earlier in the day. And to all the people with MS who have posted their questions and comments.

Further information

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

Publications

MS Trust
Factsheets
- Aimspro
- Diet
- FES (functional electrical stimulation)
- LDN
- Mitoxantrone
- Sativex
- Spasticity
- Spasticity
- Stem cell

Books
- Exercises For People With MS
- Living With Fatigue
- Tips for Living with MS

DVD
- Move It For MS (£1)

- Open Door - free, quarterly newsletter
  Spasticity and spasms articles published in the August 2008 and November 2008 issues

To order MS Trust publications
Post: MS Trust, Spirella Building, Bridge Road, Letchworth Garden City, SG6 4ET
Tel: 01462 476700
email: info@mstrust.org.uk
Web: www.mstrust.org.uk/publications

MS Society
- MS Essentials 08: Getting the best from social services
- MS Essentials 08: Getting the best from social services in Scotland

Neurological Alliance
- Getting The Best From Neurological Services
  (available to download from the MS Trust website)

NICE (National Institute For Health and Clinical Excellence)
- National clinical guideline for diagnosis and management in primary and secondary care
  (available to download from the MS Trust website)

Other documents mentioned

Prof George Ebers' study of the genetics of MS
Chao MJ, et al.
HLA class I alleles tag HLA-DRB1*1501 haplotypes for differential risk in multiple sclerosis susceptibility.
Proceedings of the National Academy of Sciences (United States of America) 2008;105(35):13069-13074.

Cochrane Review on hyperbaric oxygen therapy (HBO)
Bennett M, Heard R.
Hyperbaric oxygen therapy for multiple sclerosis.
Cochrane Database Systematic Review 2004;(1):CD003057.

New national guidelines for managing bladder problems
Fowler C.
Treating MS bladder symptoms.
Open Door 2008;November:10-11.

Health care and social care
National framework for NHS continuing healthcare and NHS-funded nursing care
London: Department of Health; 2007.
www.nhsdirect.nhs.uk/articles/article.aspx?articleId=2392

Neurofascin
Mathey EK, et al.
Neurofascin as a novel target for autoantibody-mediated axonal injury.
Journal of Experimental Medicine 2007;204(10):2363-2372.

Websites

MS Trust website - www.mstrust.org.uk
- Publications - www.mstrust.org.uk/publications
- Map of MS services - www.mstrust.org.uk/maps
- Research - www.mstrust.org.uk/research

Assist UK
0870 770 2866 / general.info@assist-uk.org / www.assist-uk.org

Disability Living Foundation
0845 130 9177 / advice@dlf.org.uk / www.dlf.org.uk

Jooly's Joint
an online community for people with MS
www.mswebpals.org

MS Society
0808 800 8000 / info@mssociety.org.uk / www.mssociety.org.uk

MS Resource Centre
0800 783 0518 / info@msrc.co.uk / www.msrc.co.uk

MS Therapy Centres
www.ms-selfhelp.org / www.mstherapycentres.org.uk
(Centres are shown on the map at www.mstrust.org.uk/information/services)

Rocky Mountain MS Center
information on complementary and alternative therapies
www.ms-cam.org

Shopmobility (national contact details)
08456 442 446 / info@shopmobilityuk.org / www.shopmobilityuk.org

Several of the organisations mentioned only provide services in Devon, although there may be equivalent services elsewhere in the UK.

Care Direct
an information service for older people in Devon being developed by the Department for Work and Pensions and Devon Social Services
0845 155 1007 / www.devon.gov.uk/caredirect

Time for Life
a free service in Devon that helps people aged 50 and over to build confidence, remain active and independent
0845 296 7997 / info@timeforlife.org.uk / www.ageconcerndevon.org.uk/tfl/

Upstream
a healthy living project in Devon that encourages stimulating creative and social activities for people's well-being and lifelong independence
01363 778029 / upstreamuk@hotmail.com / www.upstream-uk.com

Services suggested by people in the chatroom

The MS Trust has no experience of the services offered and their inclusion does not constitute a recommendation

Chillow
01392 499909 (afternoons only) / sue@soo-cool.co.uk / www.soo-cool.co.uk

Circulation Booster
0845 652 6111 / www.circulationbooster.co.uk

Emotional Logic
08453 709 706 / office@emotionallogiccentre.org.uk /
www.emotionallogiccentre.org.uk

Mus-Mate
0845 094 4674 / sales@musmate.co.uk / www.musmate.co.uk

Niagara massage pads
brand name for a massage device - available in the UK from a number of suppliers
www.niagara-massage.com

Surge of Chi aerobic exerciser
08456 120 129 / info@surgeofchi.com / www.surgeofchi.com

Glossary

Best Bet Diet (BBD) - an approach that attempts to control MS through modifying the diet. The BBD involves excluding dairy products, gluten and legumes, reducing saturated fat, non-gluten grains and alcohol and increasing white meat, fish and vegetables. It also suggests a range of dietary supplements

CHP (Community Health Partnerships) - organisations within health boards in Scotland whose role includes delivering primary care services locally and liaising with social services to provide social care

Coughlan judgement - Pamela Coughlan was badly injured in a road accident which left her with complex disabilities. She challenged the decision to move her care from the health service (where it was provided by the NHS) to social services (where she was required to cover some of the costs). In 1999 a Court of Appeal judgement ruled that if the needs of the individual were primarily health needs, the health authority was responsible as a matter of law. There is some controversy as to whether subsequent changes in NHS continuing care meet the obligations of the Coughlan judgement.

CUPID (Cannabinoid use in Progressive Inflammatory Disease) - a large randomised placebo-controlled trial testing the use of cannabinoids over three years in people with progressive MS. The study will test the hypothesis that cannabis has a role to play in protecting the nerves from further deterioration.

Darzi review - an extensive review of the future of NHS services in England. The review is called Our NHS, our future, but is generally known by the name of the health minister who is leading the project, Lord Ara Darzi

Hyperbaric oxygen therapy (HBO) - a therapy that involves breathing oxygen through a mask in a pressurised chamber

Individual Voluntary Arrangement (IVA) - a formal repayment proposal presented to a debtor's creditors via an Insolvency Practitioner. It is a formal alternative for individuals wishing to avoid bankruptcy. In Scotland there is a similar scheme called a Protected Trust Deed (PTD)

IVIg (intravenous immunoglobulin) - a treatment that involves administering blood plasma from healthy donors. The effect is to reduce inflammation and demyelination

Movicol - a type of laxative for the treatment of constipation

PALS (Patient Advice and Liaison Service) - each primary care trust and hospital trust in England has a PALS which acts as a source of information on services within the trust as well as a service for resolving problems and concerns

Plasmapheresis - a procedure involving the removal of blood plasma from the body, either treating it to remove antibodies or replacing it with donor plasma and then returning it to the body

Re-ablement - schemes run by local social services that aim to help people relearn or regain some of the skills they may have lost due to disability or ill health or to gain new skills that help them to maintain their independence

Speedicaths - a brand of urinary catheter

Transcutaneous Electrical Nerve Stimulation (TENS) - a machine that applies a small electric current to relieve pain