



# **Staying active with MS**

**Chatroom**

**15 March 2004**

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

## Pain and MS

**10 December 2003 – 10am to 7pm**

The experts:

- **Dr Barbara Chandler**  
*Rehab consultant (10am – 3pm)*
- **Liz Grey**  
*MS specialist nurse (10am – 4pm)*
- **Amanda Howarth**  
*Pain specialist nurse (1pm – 5pm, 6.30pm – 7pm)*
- **Louise Lockley**  
*Physiotherapist (3pm – 7pm)*
- **Vicki Gutteridge**  
*MS specialist nurse (6pm – 7pm)*

**Liz - MS Nurse:** Hello

**Dr Barbara Chandler:** Hello how are you?

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

**Anne:** My daughter is 29, diagnosed with relapsing remitting MS. She has pain in the soles of her feet and trouble walking. GP suggests drugs that collide with existing symptoms. Any suggestions?

**Dr Barbara Chandler:** Anne thanks for the question. Could you let us know which drugs your daughter is taking?

**Anne:** Prozac, Detrusitol, beta interferon, ibuprofen.

**Liz - MS Nurse:** Anne, do any of the drugs she currently takes help the pain or make it worse?

**Anne:** No effect.

**Liz - MS Nurse:** What drugs has she tried to control the pain?

**Anne:** None because they all collide with existing MS symptoms.

**Dr Barbara Chandler:** Anne could you explain a little more about what you mean by the term "collide"

**Anne:** Exacerbate epilepsy (self controlled), constipation, fatigue etc.

**Dr Barbara Chandler:** Unfortunately, many of the drugs we use to manage pain do have side effects. Often these can be managed.

**Anne:** Managed how? More drugs?

**Liz - MS Nurse:** Anne, Not necessarily, depends on the side effect.

**Dr Barbara Chandler:** Taking a physical approach to pain management can also be valuable.

**Anne:** Sounds good - what exactly?

**Dr Barbara Chandler:** Foot pain can result from muscle spasm. Physiotherapy assessment can be very helpful to evaluate this.

**Anne:** Many thanks. That's really useful. Have to go now.

**Ann:** Hi Ann here. I wonder if you can recommend any other drug other than amitriptyline for pins and needles in my hands?

**Liz - MS Nurse:** Ann, have you tried gabapentin or carbamazepine?

**Ann:** No I haven't but I will bear those two in mind. I think I am immune to any effect from amitriptyline from being on them for 5/6 years. Thanks.

**Maureen Ennis:** Hi. I'm interested in pain management protocols specifically for the treatment of different kinds of naturopathic pain?

**Liz - MS Nurse:** Maureen, we haven't got any specific protocols, but any protocol should include physical therapies as well as drug management.

**Maureen Ennis:** OK. Thanks

**Anne:** Anne with an 'e' again. My daughter also has anaemia. Can this have effect on pain in extremities?

**Liz - MS Nurse:** Anaemia may exacerbate pain in the extremities, so it is important to get this treated.

**Carol:** Has anyone a suggestion for the combined pain of arthritis and ms?

**Simon - MS Trust:** Carol, bear with us a moment.

**Carol:** Sorry can't stay on - I'm at work will try to come back later.

**Simon - MS Trust:** OK, we'll be here until 7

**Simon - MS Trust:** Hi Lula. Do you have a question for Liz or Barbara?

**Lula:** I have never done this before, I don't know where to start

**Simon - MS Trust:** Don't worry, just ask away

**Lula:** I am currently on gabapentin 3300mg/day. It is not working. Where do I go from here?

**Liz - MS Nurse:** Lula, Can you tell us a bit about the pain you are experiencing.

**Lula:** Yes, I have pain down the right side only. It is in my face, neck, shoulder and arm and hand.

**Dr Barbara Chandler:** Can you tell us what the pain feels like?

**Lula:** It is like I have been shot... so intense. The pain is deep, intense, sometimes burns. My arm feels very heavy. Continuous buzzing too. A pain I cannot reach, if that makes any sense.

**Dr Barbara Chandler:** Does the Gabapentin make any difference?

**Lula:** The gabapentin helps for a few weeks, then I have to up the dose because I cannot even get out of bed. The pain overwhelms my existence.

**Dr Barbara Chandler:** Often this type of pain requires two drugs, which act in slightly different ways. Have you taken any other drugs for the pain?

**Lula:** Prozac 40mg/day. The gabapentin makes me stupid and absent minded

**Dr Barbara Chandler:** It would be worth discussing with your GP the possibility of trying Amitriptyline in an initial dose of 10 or 20mg

**Lula:** I have tried lofepramine 140mg/day. I believe it's a sister of Amitriptyline

**Dr Barbara Chandler:** You may need to reduce your dose of Gabapentin if you are experiencing these side effects

**Lula:** I forgot to get my kids from school the other day and now the school have called social services. I got in my car yesterday and forgot how to start it. I am worried. My group say the gabapentin can do this

**Dr Barbara Chandler:** Lula, it sounds as if you are really having a lot of problems with your memory. I would suggest talking to your doctor and MS nurse about this and your current medication.

**Lula:** I do not know an MS nurse. I have moved here recently and apparently there is not one for my area.

**Liz - MS Nurse:** Do you see a neurologist?

**Lula:** Yes I had one but then I moved and I have to go to the bottom of the list again. I was diagnosed in February. I feel so alone with all this and now I'm losing my mind too. I just want someone to help me. I have never had a sick day in my life until February.

**Dr Barbara Chandler:** Lula it sounds as if you are really upset by all you are experiencing. Do talk to your GP or practice nurse in the first instance.

**Lula:** yes but they seem to be giving me the impression that I must just wait for my neurologist to see me because my pain is too much for them to handle

**Liz - MS Nurse:** Lula, if you contact the MS Trust letting them know where you now live they can put you in contact with your nearest MS Nurse

**Lula:** Since my diagnosis in February I have been pushed from pillar to post. It has been a hard time for me and my family

**Dr Barbara Chandler:** Do you actually have a date for an appointment with the neurologist?

**Lula:** No, they reckon March next year. It's a joke!

**Dr Barbara Chandler:** Another source of help would be a specialist rehabilitation unit. Generally they will see people within a shorter period of time. Ask your GP if you have a local neuro rehab centre

**Lula:** Sounds like a good idea, but I think I researched it before and the nearest one is miles away. I can't remember. I will check my notes

**Dr Barbara Chandler:** Lula do you have someone that you are able to talk to about how you are feeling at the moment?

**Lula:** I have the ms-people group. Apart from that no one. I don't even have any friends here yet... people think I'm a drunk because I wobble

**Dr Barbara Chandler:** You may find people in the group will know who is available in your area to provide more specialist help. The MS Trust can also let you have the name of your local MS nurse.

**Kim:** I wobble too Lula

**Lula:** Thank you, Kim :o) I have one lady chasing my referral, but I think she is the ms nurse from the wrong area. She says I am not under her area. I am waiting for her to call back with the MS nurses name for my area

**Liz - MS Nurse:** Lula, Keep in contact with her, as she will probably be able to pass you on to the relevant person.

**Ellie:** I really want to tell the panel about the pain treatment I am getting. I am on mexiletine following hospital as a day patient for a trial run on lignocaine infusion

**Liz - MS Nurse:** Ellie, Are you finding it helpful?

**Lula:** I have met two people on this treatment, but how would I get on it?

**Dr Barbara Chandler:** Mexiletine would be given through a specialist pain clinic

**Ellie:** Yes it is a specialist pain clinic. Do any of the panel have experience with the lignocaine treatment?

**Dr Barbara Chandler:** I don't have personal experience from the Rehab Centre. This type of treatment is offered by specialist pain management clinics as it requires careful monitoring

**Ellie:** Yes I know, I was on a heart monitor all through infusion, have full bloods and ECG at monthly appointments. The consultant concerned has only put 3 patients on it, apart from cancer patients. I am the third

**Dr Barbara Chandler:** It is a treatment specifically aimed at managing difficult nerve pain. How are you finding the treatment, Ellie?

**Ellie:** At first the effect wore off quickly, but from today I'm building up to 100mg twice a day. 100 seems to be more effective

**Dr Barbara Chandler:** That sounds really positive

**Ellie:** He seems quite prepared to fit me with a pump if tabs do not work, you can have patches as well, but the cost to NHS is high for them. I just thought if Lula could go to pain clinic privately, she could ask about it. The Gabapentin affected me the same as Lula

**Dr Barbara Chandler:** You ought to be able to access the pain clinic through the NHS by GP referral but there is often a waiting list that varies from area to area

**Lula:** So I must go bug my GP again

**Ellie:** I was lucky, my daughter is a nurse, and she knows the consultant!

**Dr Barbara Chandler:** Yes, I would discuss things with your GP again

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

**Kim:** Yes sorry I've been to loo

**Lula:** At least you can feel it... I can't! lol

**Kim:** I'm having a catheter next week, Lula

**Lula:** I am holding my own with mine by timing it. I have the odd mistake but hey

**Ellie:** Liz, if it were you, would you want me to contact you and tell you about my pain clinic treatment?

**Liz - MS Nurse:** Ellie, your nurse would probably be interested in hearing about your treatment.

**Ellie:** OK, I had better leave a message on her line

**Lula:** How do you get yourself placed on a trial?

**Liz - MS Nurse:** Lula you usually get placed on a clinical trial via your neurologist

**Lula:** At the moment the only thing that really helps my pain is cannabis

**Ellie:** My nice Dr says cannabis is fine. He is happy for me to take it with the Mexitil. Have to go now. Bye all and thank you for your advice, I feel a bit like a guinea pig, but privileged

**Tony:** Has there been at research in to the effects of Radon?

**Liz - MS Nurse:** Not that we're aware of in relation to MS. We're just looking it up

**Tony:** I go to the old gold mines in Austria annually. I feel that it does help with my MS

**Simon - MS Trust:** There has been some research in Norway into radon as a possible trigger for MS. It is rather hypothetical at the moment and there is a range of other environmental factors that have been suggested as possible triggers over the years

**John:** That trigger seems to help my MS and keeps me very stable or not any worse

**Simon - MS Trust:** The only things I can see in the literature - admittedly after a brief scan - are about radon as a risk factor for MS, not as a treatment. But if the trips to the mines are helping you, that's great

**John:** What do you think about HBO?

**Liz - MS Nurse:** There is very little evidence, some people find it useful, others don't. Some people feel worse - although this is usually transient.

**John:** When and in what form will cannabis be available?

**Liz - MS Nurse:** We don't know - nothing has been put forward for a license yet. It won't be in a form for smoking.

**Simon - MS Trust:** John, there's information about the state of play with cannabis in a factsheet on the publications page of the MS Trust website. Go to the About MS section and follow the links

**Simon - MS Trust:** Hello Tony

**Tony:** Can you get reflexology on the NHS?

**Liz - MS Nurse:** It's dependent on the local area. Some practitioners do reflexology as an addition to their usual role. MS therapy centres are sometimes able to offer it for a voluntary contribution.

**Tony:** What practitioners do this and are they qualified?

**Liz - MS Nurse:** There is the British Complementary Medical Association, which should be able to tell you how to verify if a practitioner is suitably qualified. They can be contacted by email [info@bcma.co.uk](mailto:info@bcma.co.uk) or there is a website [www.bcma.co.uk](http://www.bcma.co.uk)

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

**Patricia:** My current problem is knee pain and knee weakness. Not very mobile with it. Only relief is Valium, which I use sparingly. Any ideas?

**Dr Barbara Chandler:** Knee pain can result from altered muscle balance across the knees. Often a physiotherapy opinion can be very useful.

**Tony:** Why do doctors still prescribe Valium when there are better drugs on the market?

**Patricia:** I am on Neurontin and Prothiaden, which help with other pain, but not the knees. Which better drugs do you know of?

**Dr Barbara Chandler:** There may sometimes be a specific reason for using Valium (Diazepam). Generally, as you say, we would use alternative and more specific medications

**Tony:** I use dantrolene for muscle relaxant and Vioxx for the anti-inflammatory

**Dr Barbara Chandler:** I would certainly recommend a physio assessment. Knee pain is very common and may not necessarily be a direct effect of the MS.

**Patricia:** I live in Dublin. I have been to physio with no MS experience. Should I go to MS physio?

**Dr Barbara Chandler:** If possible, it would be helpful to see a physio with MS experience. An assessment for possible knee joint problems would also be valuable if you cannot access a specialist physio.

**Simon - MS Trust:** A question sent in beforehand by Marilyn - I had my trigeminal neuralgia treated by radiosurgery (the 'gamma knife') and have been pain free for about two years but I was warned the cure might not be permanent. Should the TN return, would it be safe to recommence the combination of carbamazepine / gabapentin now that I am taking modafinil?

**Liz - MS Nurse:** that should be fine - you will need to discuss it with your GP if the TN returns.

**Patricia:** I now have a low white cell count - low immune system - because of beta interferon. What should I do to get it back to normal? eg diet, exercise, etc.

**Dr Barbara Chandler:** Are you asking about diet in relation to pain management?

**Patricia:** Yes, can diet help pain management?

**Liz - MS Nurse:** Patricia, how long have you been on beta interferon?

**Patricia:** About 5 months

**Liz - MS Nurse:** The low white cell count will probably return to normal over the next few months

**Dr Barbara Chandler:** Knee pain due to joint problems can benefit from weight reduction if someone is overweight. Physio can offer guidance in this respect

**Patricia:** Thank you Barbara, but I have lost a lot of weight since been diagnosed, and am now trying to put some back on! Which is difficult with a healthy eating plan!

**Dr Barbara Chandler:** Yes it can be really difficult to gain weight when you have lost it. I don't really know of any other dietary manipulations that can specifically help with pain

**Patricia:** Is there any drug apart from Valium, do you think, that will relieve this knee pain/weakness? Also, do you think yoga or pilates is better?

**Simon - MS Trust:** Patricia, later in the session we'll have a physiotherapist in the room. She may be better placed to discuss yoga and pilates. She'll be online from about 3pm

**Dr Barbara Chandler:** Have you been given the Valium for the knee problem?

**Patricia:** Well, initially when I was very bad, my GP gave me a prescription, but I think he didn't really know, as I suggested it!

**Dr Barbara Chandler:** Valium is a drug that has a general relaxing effect but if you have problems with muscle spasm then there are better drugs such as baclofen. Valium is not a painkiller and again something more specific would be preferable

**Patricia:** I shall "talk" to the physio after 3 regarding yoga. Thank you for advice Dr Barbara, Simon, & Liz - you have been very helpful. Bye for now!

**Dr Barbara Chandler:** Patricia thanks for taking part I hope it's been helpful

**Dino:** Are we any closer to a cure?

**Liz - MS Nurse:** Dino - Research continues

**Simon - MS Trust:** Hello Amanda

**Amanda - pain nurse:** Hi Simon

**Dino:** Is Codydramol a painkiller for MS?

**Amanda - pain nurse:** It's a general painkiller used for many types of pain, not just MS

**Dr Barbara Chandler:** Codydramol is a painkiller for general aches and pains. It can be helpful. It is not useful for nerve pain.

**Dino:** I have always got a general ache, is this normal?

**Dr Barbara Chandler:** This may be due to the way you are sitting or the stiffness in your muscles. It would be helpful to have a physio assessment and advice

**Dino:** What painkiller would you suggest for nerve pain?

**Dr Barbara Chandler:** You should discuss your pain with your doctor. If the pain sounds like nerve pain then a small dose of Amitriptyline or Gabapentin may help

**Dino:** Amitriptyline causes me severe sweats does Gabapentin have the same side effects?

**Dr Barbara Chandler:** A lot of people seem to tolerate Gabapentin very well. It is best to start at a low dose and then increase according to effectiveness.

**Simon - MS Trust:** A question emailed in in advance by Deanna - I have been told that I may have a condition linked to my MS called glossopharyngeal neuralgia. I already have trigeminal neuralgia, for over ten years now, which is medically controlled but what is glossopharyngeal neuralgia? And what can be done for it? It is very painful.

**Amanda - pain nurse:** I'm afraid that this is not something I have come across but would have thought it may respond to treatment in the same way other neuralgias do.

**Simon - MS Trust:** We've checked the textbooks for glossopharyngeal neuralgia and it seems to be a rare condition. The books mention just a single case study. It is probably best to consult your neurologist about treatment

**Mandy:** I get a lot of stiffness and pain down my spine. Can you tell me if there is anything I can take to loosen it?

**Amanda - pain nurse:** The best thing to think about is maybe some physiotherapy to help the muscles in your back. There will be a physio in the chat room later on.

**Mandy:** OK thanks. At the moment I take Zanaflex to help relax my left leg but it is still very stiff is there anything else that could help?

**Dr Barbara Chandler:** First of all it would be worth checking whether you are on the most appropriate dose of Zanaflex. There are other muscle relaxants that can be used alongside or instead of Zanaflex

**Mandy:** I can take up to 24mg a day

**Dr Barbara Chandler:** It is possible to increase the dose gradually up to 36mg but it depends whether you experience side effects. Side effects are more common at the higher doses

**Mandy:** What would the side effects be?

**Dr Barbara Chandler:** The commonest is drowsiness

**Mandy:** I get tired quick if I try to do too much

**Dr Barbara Chandler:** Getting tired may be part of the MS or it may be exacerbated by the medication. You may have to weigh up the benefits of an increase in the medication versus the side effects

**Mandy:** I think it's the MS that makes me tired and not the medication. I always push myself when I feel a little stronger

**Dr Barbara Chandler:** Perhaps you should discuss with your doctor a gradual increase in the Zanaflex. Your doctor will need to check a blood test at intervals

**Mandy:** OK

**Dr Barbara Chandler:** I would also recommend asking for a physio assessment

**Liz:** I wanted to ask about Capsaicin cream for hypersensitivity. How can I apply it without increasing the hypersensitivity problems (and the foot drop)?

**Amanda - pain nurse:** Does the increase in hypersensitivity just last whilst the cream is being applied or longer? Have you tried putting local anaesthetic cream on beforehand?

**Liz:** I can apply it quite painlessly, but the pain and lack of mobility develop over the next few hours.

**Amanda - pain nurse:** Is that with the capsaicin or with local anaesthetic?

**Liz:** I haven't actually tried local anaesthetic but how could I be sure it wouldn't make my leg dead then ever?

**Amanda - pain nurse:** Liz - The local anaesthetic only works on the area it is applied to, therefore it shouldn't make you leg "dead"

**Liz:** No, but the touching will.

**Amanda - pain nurse:** What it can do though is dampen down the hypersensitivity that is often exacerbated by the capsaicin. If you feel that applying creams is making the problem worse then maybe you need to go back to your doctor to explore further treatment options

**Liz:** I have very bad digestive and bowel problems, which are increased by painkillers.

**Amanda - pain nurse:** There may be things other than tablets to try such as a TENS machine or acupuncture

**Liz:** TENS and acupuncture involve touching.

**Amanda - pain nurse:** They do, but in the long run it doesn't necessarily mean they will exacerbate the pain.

**Veronica:** I get a weird pain in my right leg sometimes. It feels like someone is pouring a cup of hot tea down my thigh. The pain eases the lower the 'tea' gets. Is this common or is it just me?

**Dr Barbara Chandler:** This sounds very like a nerve type pain, which is very common in MS

**Veronica:** I'm glad it's not just me! I didn't know whether to mention it to my doctor or not. What could he do about it?

**Dr Barbara Chandler:** You could certainly discuss it with your doctor and he/she will know what you are talking about. Your doctor will probably suggest some medication to help with the sensation

**Veronica:** Is there anything I can do at home? ie rest more? Or will I have to take medication?

**Dr Barbara Chandler:** There are various drugs. Ordinary painkillers like Paracetamol do not have any effect on this sensation. Does the pain occur at any particular time of day or on relation to any particular activities?

**Veronica:** It's worse when I'm standing for a long time, but it just comes and goes. The last bad patch was a month ago and I had 'tea' pain for 3 weeks.

**Dr Barbara Chandler:** Pain is variable. Sometimes it is affected by your posture. Some people find their pain is exacerbated if they are very tired. Environmental temperature also can have an effect

**Veronica:** I'd better go and see my doctor then and see what he recommends. And I'll try to keep awake and the right temperature!!

**Dr Barbara Chandler:** Have a chat with your doctor. Thanks for your questions. Best of luck.

**Veronica:** Thanks Dr Chandler.

**Holly:** I get bad headaches - is that due to MS?

**Liz - MS Nurse:** It can be, but there are other causes. Have you spoken to your GP about them?

**Holly:** I have but nothing he has done has helped

**Liz - MS Nurse:** What have you already tried?

**Holly:** Not sure of names - think they were migraine drugs

**Liz - MS Nurse:** Is there anything that you've found triggers the headaches?

**Holly:** Not found a trigger. Seems more likely in the afternoon, but not every afternoon

**Liz - MS Nurse:** Holly, sometimes if you take analgesia at the first sign of the headache it can stop it developing into something more severe.

**Holly:** Are these over the counter things or do I need to go to the doctor?

**Liz - MS Nurse:** It depends what works - often starting with paracetamol is enough. However if these are not strong enough you may need to see your GP for something on prescription. Acupuncture is often helpful for treating headaches

**Simon - MS Trust:** We've had an email question from Australia regarding abdominal pain. The person was hospitalised for very acute pain for which no valid reason that was found (the surgeon was called to consult and on both occasions refused to do a laparoscopy to rule out things that didn't show up on ultrasound or CT scan). He has put this pain down to being caused by MS. Is it possible (it also had nothing to do with bowel or bladder)?

**Dr Barbara Chandler:** It is possible that the pain could be a type of neurogenic pain (nerve pain) that is due to the MS. Obviously it is really important to ensure that it is not due to any other problem. A common contributor to abdominal pain is bladder dysfunction and this should be checked out by a Urologist.

**Amanda - pain nurse:** There is a lot of undiagnosed abdominal pain generally in the population - its therefore difficult to establish whether its due to the MS or something that they would have experienced regardless

**Jo:** At the moment I get bad leg pains sometimes. I have tried cannachoc, not very successful. Exercise helps a bit.

**Dr Barbara Chandler:** Leg pains can be due to muscle imbalance or spasms. If exercise helps a bit you may find that some specific advice on exercise from a physiotherapist would be helpful

**Simon - MS Trust:** Amanda, earlier someone was asking about reflexology as a way of handling pain. Have you had experience of using this?

**Amanda - pain nurse:** I have had some reflexology training as part of my aromatherapy training, however I tend not to use it as it can be quite painful. I have got a colleague working in a pain clinic who uses it as part of her practice.

**Dr Barbara Chandler:** That's really interesting Amanda.

**Amanda - pain nurse:** The problem is finding somewhere to access it on the NHS as it can become expensive it sought privately.

**Dr Barbara Chandler:** Is it people who already have hypersensitivity that experience pain?

**Amanda - pain nurse:** No, its often painful for anyone (including me!!!) - a lot of pressure is applied and therefore some people don't like it

**Dr Barbara Chandler:** I hadn't realised it could be painful

**Simon - MS Trust:** Is there a recognised body that regulates reflexologists?

**Amanda - pain nurse:** Yes, there are two main reflexology organisations who can recommend trained practitioners - their contact details are [www.britreflex.co.uk](http://www.britreflex.co.uk) or [reflexologyuk@hotmail.com](mailto:reflexologyuk@hotmail.com)

**Linda:** Hello everyone. My problem is extremely sharp shooting pains in my head. They are so severe that I can hardly breathe. Mostly they don't last long. But I had a bad attack in the spring that went on every 3 seconds day and night for over a fortnight. Paracetamol only slightly dulled them

**Dr Barbara Chandler:** Shooting pains can happen in MS. Have you discussed this with your doctor? That sounds like what is called a "paroxysmal" symptom. It can be helped by a drug called Carbamazepine

**Linda:** At the time I didn't realise it was anything to do with the MS. Thanks, I shall mention that to my GP

**Linda:** I have been having the shooting pains in a different part of my head over the last week or so, and my walking has got MUCH worse. Does this mean it is another area of nerves being damaged?

**Dr Barbara Chandler:** Linda I would suggest that you see your neurologist for a review as things have deteriorated.

**Linda:** I am due to see him in the New Year, February I think. Should I try to go before then?

**Dr Barbara Chandler:** I would discuss this with your MS nurse and she may advise you to bring forward the appointment.

**Linda:** No such thing as an MS nurse in my area!

**Dr Barbara Chandler:** As you describe a sudden worsening of symptoms I would speak to your GP regarding advice from your neurologist

**Holly:** Amanda mentioned aromatherapy - how does this work?

**Amanda - pain nurse:** Aromatherapy seems to help some people with pain especially if they are having problems sleeping and with tight muscles. The essential oils are massaged into the painful areas and people report benefits including improved sleep, relaxation and feeling of well-being

**Andre:** I have recently been getting severe head pains, which my doctor says is Trigeminal Neuralgia. Is there any thing I can do about it?

**Dr Barbara Chandler:** Has your doctor suggested any treatment?

**Andre:** She has put me on a low dose of Amitriptyline, but I am still getting the pains

**Dr Barbara Chandler:** You may find it helpful to discuss with your doctor increasing the dose of Amitriptyline. Or it may be that an alternative drug such as Carbamazepine would be more beneficial

**Andre:** I am on a dose of anti-depressants will the Carbamazepine have any effect on them?

**Dr Barbara Chandler:** Check with your doctor but generally it is OK to take Carbamazepine in this context alongside the antidepressant

**Andre:** I will talk to her and see what she says - thank you

**Dr Barbara Chandler:** Thanks Andre

**Geraldine:** I've always had a bit of back pain but since I've been diagnosed it's been quite bad at times. I'm not taking anything for it. Paracetamol don't help.

**Liz - MS Nurse:** Have you seen a physiotherapist?

**Geraldine:** No. Might massage etc help?

**Amanda - pain nurse:** Massage might help but the physio would be in a good position to advise you

**Liz - MS Nurse:** Possibly, back pain is sometimes caused by problems with posture.

**Geraldine:** So nothing to do with the MS after all?

**Liz - MS Nurse:** Geraldine, it may or may not be linked to your MS

**Simon - MS Trust:** Dr Chandler has now left and Louise Lockley, a physiotherapist, has joined the chatroom

**J:** Have you any ideas re-my curling toes when walking please?

**Louise - physiotherapist:** This can be a common problem. There can be a number of reasons for curling toes, could you give me more information?

**J:** I used to wear an EMS. I found my toes curled when walking. I now wear a orthotic aid. I still have pain re: curling under when I walk, I've had botox injections but no good

**Louise - physiotherapist:** What kind of orthotic do you use?

**J:** This curling under of course disturbs my balance. Even bare foot they curl involuntary. Orthotic is like plastic boot

**Louise - physiotherapist:** Curling of the toes can be due to a number of reasons. Spasticity, because of balance problems, or can be due to shortened toe muscles underneath the foot. It would be helpful if you could see a neuro-physiotherapist to try to find out why they are curling. Have you seen a physio?

**J:** Yes I used to see a neuro-physio. I don't anymore. It seems I wasn't asked to go again as what they did didn't help. Botox and casts for underneath the toes. Is there any other answer to it?

**Louise - physiotherapist:** It may be worth seeing the physios again and looking at stretches for the foot and toes and general exercises for this leg as well as a further orthotic assessment

**Simon - MS Trust:** Hello Peter and George. Do you have a question for Amanda, a pain nurse specialist, or Louise, a physio?

**PeterC:** I suffer severe pain in the perineum. Gabapentin did not help. Any advice please?

**Amanda - pain nurse:** You need to make sure you have tried a sufficient dose of Gabapentin

**PeterC:** I was up to 1,800 mg per day.

**Amanda - pain nurse:** Peter - have you tried anything else?

**PeterC:** I take cocodamol on a regular basis. I tried one of the anti depressants but that made me depressed!!

**Amanda - pain nurse:** Peter - you may benefit from a nerve block that can be carried out by a pin clinic - you could ask you GP or neurologist to refer you

**Amanda - pain nurse:** Peter - sorry, I meant a pain clinic not a pin clinic!

**PeterC:** Amanda. I have tried that but no success. Physio sometimes helps and I am currently trying an osteopath. Perhaps pins might be the answer to my problem!!!

**Amanda - pain nurse:** Peter - well joking aside - acupuncture may help! What kind of a nerve block did you have?

**PeterC:** Amanda. It was a morphine injection in the spine. There was something else with it but cannot remember what. Few years ago now. Had my first acupuncture last week.

**Amanda - pain nurse:** See how the acupuncture goes as it can take a while to work - good luck.

**PeterC:** Amanda, thanks. Bye

**George:** I have a constant ache in my hips and back. Any thoughts?

**Louise - physiotherapist:** Could you give more information about the pain. How long have you had it? Can you describe the pain? Does anything make it better or worse and have you had any treatment for it?

**George:** it's just a constant dull ache. Bad when I've been sitting for a while, but always there.

**Louise - physiotherapist:** Have you seen a physio for the pain?

**George:** No. Doctor tried a few painkiller things but not that

**Louise - physiotherapist:** As your pain worsens when sitting for long periods it may be helped by physio and increasing your general activity and movement throughout the day. Why not contact your GP for a referral to your local physiotherapist? Also try not to sit for too long, break up the time sitting, even if you just stand up every 30 minutes?

**George:** What does physio involve? Is it just stretching exercises?

**Louise - physiotherapist:** No. A physio may be able to identify problem areas such as specific weak or stiff muscles or stiff joints in the back and then suggest specific treatments. Treatments may be stretches, strengthening exercises, posture advice, general advice about moving and activity or the physio may mobilise or manipulate the joints of the spine if this is needed.

**George:** Sounds good - and this is on the NHS?

**Louise - physiotherapist:** Yes, George. Physio is free. You can get a physio assessment on the NHS through your GP, sometimes the waiting lists are rather long, depends on where you live, but I would give it a go

**Patricia:** Hi, I was on this morn about knee pain/weakness, and the doctor thought perhaps some physio might help? What exercises would you suggest - also yoga or pilates best?

**Simon - MS Trust:** Patricia's question fits with one emailed beforehand by Malcolm, who asks about the role of exercise in managing pain, particularly pilates

**Louise - physiotherapist:** Exercise is important to maintain flexibility and strength of muscles and joints. Areas of stiffness and pain can result in pain. The most common area is in the lower back

**Patricia:** Thank you Louise - but I'm "chatting" from Dublin, where physio is unfortunately not free

**Louise - physiotherapist:** Pilates is a good form of exercise for "core stability" in the back and abdominal regions. Yoga is excellent for flexibility and can challenge your balance

**Patricia:** Thank you Louise for your help and advice. Bye for now.

**Luckyden:** I take gabapentin for pain, is that all there is?

**Amanda - pain nurse:** No. It depends on the type of pain you are experiencing. Have you tried anything else?

**Luckyden:** Cannabis. I get just really bad leg pain, and also back pain but I think that's down to posture

**Amanda - pain nurse:** Physio may help and there are other drugs that can help

**Louise - physiotherapist:** Posture can cause pain, why not see a physio for some advice?

**Luckyden:** I found yoga helped, but I had to stop, as I couldn't get there

**Louise - physiotherapist:** I am glad yoga helped and this is encouraging as general exercises may help also and you could do these at home. Why not see a physio for advice?

**Luckyden:** Will do, thanks

**Kate:** I feel like my skin is burning - what can be done?

**Chris:** Like Kate, my skin feels as if it's burning at times (particularly on my hands arms and neck). Happens mainly in the evening and at night. Is this due to my MS?

**Amanda - pain nurse:** It sounds like it is due to the MS

**Chris:** I always scratch my burning skin (naughty!) Is there any ointment that could help?

**Amanda - pain nurse:** Do you currently use anything for it?

**Chris:** No

**Amanda - pain nurse:** It would be worth seeing your neurologist or GP as there are some drugs that can help with this sort of irritation

**Chris:** Thanks for your advice, Amanda. I'll do that. I must go now. Thanks for running the chat room. Merry Christmas to you all

**Simon - MS Trust:** Thank you Chris, and a happy Christmas to you too.

**Andre:** The muscles in my hands seem to spend the majority of the time in heavy spasm. What can I do?

**Louise - physiotherapist:** Is the spasm just in your hand or in other parts of your body?

**Andre:** It spreads up the arm when I am tired, and into my legs

**Louise - physiotherapist:** Are the spasms painful?

**Andre:** Very

**Louise - physiotherapist:** Do the spasms close your hands?

**Andre:** Yes

**Louise - physiotherapist:** Are there any triggers to these spasms?

**Andre:** Stress for my hands and tiredness in my arms and legs

**Louise - physiotherapist:** OK it is important to know the trigger factors as this is the first step to controlling them. Secondly keeping the hands flexible and the muscles stretched is important, you may need some stretches for the muscles that are in spasm. There are other options if these simple steps do not help and I would suggest that you see your neurologist as there are some medications that may help. Also it may be helpful to see a neuro physio as they can give a full assessment. In summary, I would suggest seeing neuro physio and neurologist. Try stretching the hands out fully regularly in the day. Hope this is helpful

**Andre:** Thank you for your help advice. Have to go now. Happy Christmas to you all

**Jim:** Are there alternative medicines that are good for pain?

**Amanda - pain nurse:** What do you mean by alternative medicine?

**Jim:** Herbal things or acupuncture. That sort of thing

**Amanda - pain nurse:** Many people use complementary therapies such as acupuncture, aromatherapy and reflexology for pain - is this the sort of thing you mean?

**Jim:** Yes, that's it

**Amanda - pain nurse:** They can be useful - they often don't get rid of the pain but can help to reduce it a bit and make people feel better

**Ellie:** Jim I have found massager with oil of lavender is good for pain

**Jim:** Are acupuncture, aromatherapy and reflexology the best ones, or do other things help too?

**Amanda - pain nurse:** They are the ones I am used to using in the clinics I have worked in. There are other things available but I don't have any experience of them

**Ellie:** For Louise, I have been doing aquafit on a joint scheme with Primary Health Trust and Leisure Services. I have been very impressed and have done well on it. Do they do this in other areas?

**Louise - physiotherapist:** GPs can now prescribe exercise on prescription throughout the country

**Ellie:** Louise, they call it the Terms scheme here, and the physio at Hurstwood Park suggested my GP refer me, I had to go twice a week for ten weeks and have found it such a help

**Louise - physiotherapist:** I am very pleased you found it helpful. It is an excellent service and you seem to have found an exercise that you enjoy which is perfect. Well done!

**Ellie:** Yes, I have finished now, but have joined the club, and still go once a week, and have had a gentle exercise routine worked out for my in the gym

**Louise - physiotherapist:** You are a shining example to us all!

**Ellie:** Well I wouldn't go if I did not enjoy it. Sometimes it's an effort to go but I always feel better for it

**Amanda - pain nurse:** I have to leave now - hope to be back later

**Simon - MS Trust:** Thanks Amanda. Hope to see you again later

**Ellie:** Does anyone know the benefit, or otherwise of Hyperbaric Oxygen?

**Simon - MS Trust:** Ellie, there has been some research but this has tended not to find much benefit. However, some people do find it helps some symptoms. Do you use HBO?

**Ellie:** No, I think it is very expensive at Hove, but I believe they will meet you on the cost if you cannot afford it

**Jim:** I tried that when I lived near Reading. Helped with fatigue for a while

**Ellie:** Did it last Jim?

**Jim:** For a while. It started to wear off after a few days, but I enjoyed going along

**Malcolm:** My interest relates to the relevance of exercise in managing pain. What are your thoughts?

**Louise - physiotherapist:** Exercise can be very helpful but this depends on the type of pain. Pain related to posture, stiff or weak muscles can be helped with exercise.

**Simon - MS Trust:** Hello Jill

**Jill:** Hello - I thought I'd just pop in to hear what's being said!!! My experience of pain is minimal. I do get spasms, which can be annoying especially at night time!

**Louise - physiotherapist:** Can I be of help with the annoying spasms?

**Jill:** I do a lot of stretching exercises and I swim most weeks but any help will be very welcome :-)

**Louise - physiotherapist:** What kind of spasms do you get?

**Jill:** In my left leg - a sort of twitching. During the day I can shake quite a bit but this stops when I place my foot/feet squarely on the ground.

**Louise - physiotherapist:** The spasms at night, do they wake you up and do they cause your legs to move?

**Jill:** I am aware of them when I do wake up but I think it's my bladder that wakes me up. On the whole I sleep for about 7 hours from 1 - 8am, which is not bad going.

**Louise - physiotherapist:** Bladder problems can make spasms worse. Stretches can be helpful and you are doing these already. Sometimes your sleeping position can influence the spasms

**Jill:** What is a good sleeping position then?

**Louise - physiotherapist:** It may be helpful to do your stretches before going to bed and try different sleeping positions to see if this helps. Generally if the spasms straighten your legs then try sleeping with the knees and hips bent on your sides. If on your back then put a pillow under your knees. If the spasms bend the legs then you need to lie with the legs in a more straight position.

**Jill:** Malcolm what sort of pain do you get?

**Malcolm:** Just general life pains, which I feel, are a result of lack of activity and the body generally breaking down.

**Jim:** I find I seem to ache when I get tired

**Malcolm:** I just ache!

**Jill:** All the time or is it worse when you wake in the morning or after a long day?

**Malcolm:** definitely towards the end of the afternoon. I actually feel it is also posture related.

**Jill:** Malcolm re posture - do you ever change your position or do you sit in the same chair a lot? I invested in a rise and recline chair so I can have me feet up when sitting comfortably and find this helps me. It also helps keep ankles looking neat and trim!

**Louise - physiotherapist:** Malcolm and Jim - is the tiredness fatigue? If so an assessment by a neuro Occupational Therapist might be helpful as they can advise about fatigue

**Jill:** Jim, can you avoid getting too tired?

**Malcolm:** I'm actually quite mobile during the day but when I am seated its generally in one of two chairs.

**Jim:** I walk with crutches, and this tires me out on busy days - especially in the afternoon

**Malcolm:** I am thinking about trying either yoga or pilates to help correct my posture, regain some strength and hopefully to try to deal with the aches

**Louise - physiotherapist:** This sounds a great idea. You might also benefit from an assessment from a neuro physio to guide you for specific areas for your body that may be weak or stiff

**Jim:** I've been wary of doing exercise in case it tires me even more - makes me sound like a couch potato :-)

**Malcolm:** Pilates seems slightly more appealing because of the degree of movement and the support offered by the machine. Do you have any experience?

**Jill:** I really recommend seeing a neuro physio. I found that I was standing badly and became much more aware of my posture as a result of her advice. I believe that yoga is a very good means of exercise - stretching . . .

**Louise - physiotherapist:** I agree with Jill but pilates would supplement a specific exercise programme. Pilates however does not involve a machine, do you mean another form of exercise?

**Jill:** Seeing a qualified neuro physio is best because s/he can bear in mind your skeletal system etc as well and I don't know how aware pilates teachers are of such needs.

**Jill:** Jim its a strange thing but often exercise can help make us feel more energetic. It certainly does that for me.

**Louise - physiotherapist:** It is common to not want to do exercise if it tires you out but it may be helpful to start with a small amount of exercise and slowly build up. A physio could guide you

**Jim:** Oh dear, another excuse shot down :-)

**Louise - physiotherapist:** Sorry, Jim!!!

**Jill:** Oh Jim, do give exercise a try. Your GP can refer you to a neuro physio.

**Jim:** Exercise on the NHS? Is there no escape?

**Jill:** No escape, Jim.

**Louise - physiotherapist:** Jim, we seem to be ganging up on you! However exercise can be enjoyable I promise. It would be good for you to have advice about exercise form a physio

**Malcolm:** The pilates studio I viewed had something called a "reformer", a kind of moving platform.

**Jill:** Reformer - is this like the walking thing at the gym - like walking against an escalator going the opposite way?

**Malcolm:** The reformer has a flat platform that you sit, stand or lie on. As you move it moves. Looked like fun to me.

**Malcolm:** Sorry how is a neuro physio different from a normal one?

**Louise - physiotherapist:** A neuro physio specialises in seeing people with neurological problems and knows a lot about movement and the difficulties caused by neurological deficit

**Jill:** It's been good to talk and thanks for the advice re sleeping positions, Louise.

**Simon - MS Trust:** It's been useful, Jill, thanks for your input

**Louise - physiotherapist:** Jill, good luck

**Malcolm:** On another subject. I have read that breathing exercises can help with pain. Something similar to meditation perhaps. Any thoughts

**Louise - physiotherapist:** Breathing exercise can help with relaxation, so if pain causes muscles to be tense then they could be beneficial. Also generally these exercises are done in good postures so it may have a knock on effect

**Malcolm:** When there is something new to try I always feel we have a possibility of improving things.

**Simon - MS Trust:** Hello Kathy. Do you have a question on pain for Louise, a physio, or Vicki, an MS nurse?

**Kathy:** I have had a problem through a mistake made when I had a lumbar puncture. The doctor doing the test hit a number of nerves causing me additional pain on top of my MS. I do not know what pain is caused by the mistake or by the lumbar puncture. Will the lumbar puncture pain go - even after nearly three years since the mistake happened?

**Louise - physiotherapist:** How is this pain affecting you at the moment?

**Kathy:** I get a burning sensation down my sciatic nerve plus pain in the feet.

**Louise - physiotherapist:** Have you seen a neurologist about this pain?

**Kathy:** Yes. I have just completed a short and very strong course of steroids, which have not helped much.

**Louise - physiotherapist:** Were the steroids for a relapse or for pain?

**Kathy:** To prevent a downward turn in my condition.

**Louise - physiotherapist:** Do you take any medication for the pain?

**Kathy:** I have 25 mg to 50 mgs of Amitriptyline for pain

**Louise - physiotherapist:** is this helping?

**Kathy:** It seems to help very little at present.

**Louise - physiotherapist:** Kathy, it may be worth speaking to your neurologist again about this pain, Vicki what do you think?

**Vicki - MS nurse:** I agree. 25-50mg amitriptyline is still quite a low dose. It may not be at a therapeutic level for you. Has your doctor added Tegretol at any time?

**Kathy:** No she has not. Thank you. Will follow it up.

**John M:** It's not exactly pain, but why do people with MS get so much pins and needles?

**Simon - MS Trust:** Do you experience a lot of pins and needles, John?

**John M:** Yes, in my feet - it's more of an irritant than a pain

**Vicki - MS nurse:** Tegretol may be worth considering this. Very effective for neuropathic pain. It needs to be the slow release form.

**Simon - MS Trust:** Vicki, would that also be useful for John's pins and needles?

**Vicki - MS nurse:** It can also help the pins and needles type of pain.

**John M:** It's not so much how to deal with it, but why we get it

**Kathy:** What are the side effects of this drug, please? I am very cautious about drugs since I believe that a drug triggered my MS.

**Vicki - MS nurse:** The side effects are possible slight nausea, dizziness. The slow release keeps risk of this to minimum. It is a very safe drug and well tolerated

**Amanda - pain nurse:** Hi - I made it back

**Simon - MS Trust:** Welcome back Amanda. John has been asking why people with MS get pins and needles. Is this something you can help with?

**Amanda - pain nurse:** John - the pins and needles is a classic sign of MS - it's caused by the damage to the nerves from the demyelination. They fire off and do all sorts of odd things which is why you get the pins and needles

**Vicki - MS nurse:** That's right. They are 'exposed' as a consequence of the myelin sheath being damaged

**Kathy:** Thanks for the help re drugs. One last thought, have you heard of anyone else starting MS as a result of a Zoladex injection?

**Vicki - MS nurse:** No, that's not something I've heard of

**Vicki - MS nurse:** Have we also mentioned how important it is to include emotional well being and relaxation in managing pain?

**Louise - physiotherapist:** We did mention relaxation and breathing exercise before but if you want to expand that would be great

**Amanda - pain nurse:** Relaxation and breathing techniques are things done frequently in pain clinics for pain management one of the big benefits is the effect that both can have on sleep and if people can get a good nights sleep then they can cope much better with their pain.

**Vicki - MS nurse:** A lot of pathways are shared that influence pain and perception of pain

**Simon - MS Trust:** I'm afraid we have to wrap up the session now. Thanks to Vicki, Louise and Amanda and to Barbara and Liz who were online earlier.