



# **Pain and MS**

## **Chatroom**

**24 September 2009**

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

# Pain and MS

**24 September 2009 - 10am to 7pm**

- **Dr Ilan Liebeman** - *pain consultant*
- **Kate Golding** - *MS nurse*
- **Dr David Rog** - *neurologist*
- **Vicki Matthews** - *MS nurse*
- **Linda Miller** - *MS specialist physiotherapist*
  
- **Dr Willy Notcutt** - *pain consultant\**

*\* Dr Notcutt was unable to take part in the chatroom but supplied general comments on pain management having seen some of the questions that were asked on the day*

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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 during the chatroom is 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](mailto:infoteam@mstrust.org.uk)

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**Simon - MS Trust:** Welcome to today's chatroom on pain and MS

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**Steve:** I get pains around my rib cage - what I've seen called the MS hug, which seems accurate. Quite brief episodes but makes me feel I've just been hugged by a bear. Any thoughts on dealing with this?

**Andy:** I also have the MS hug. It feels like a tight band all around my rib cage and is worse when I sit down. My symptoms of MS started with a numb bottom. I take gabapentin which I think helps a bit. The pain gets really bad when I pick up anything much over 5kg

**Linda:** I also experience this chest banding or hug. The pain is 8/10 whilst it's going on. I currently take 10mg of baclofen as soon as the pain starts. Is this the best way of dealing with this? I am taking up to 50mg of baclofen daily.

**Steve:** Linda, how often do you get this?

**Linda:** On a bad day can get the banding four or five times at different times of the day. Then will go several days with nothing, then off we go again. Even happens when I'm driving - very scary!

**Dr David Rog - neurologist:** From what you've said your symptoms are very variable. Have you observed anything that triggers / worsens them? Might be worth re-visiting this and even keeping a diary of what you do / how you sleep etc.

**Linda:** Thanks for the advice will try anything that will help. Don't sleep well due to back spasms making sleeping positions difficult. The baclofen does help this. I don't take anything else. Must admit everything is worse when I'm tired

**Dr David Rog - neurologist:** It might be worth discussing the dose and timing of the baclofen with your neurologist and MS nurse. Certainly it is likely to be beneficial to have decent levels of baclofen in the blood before you try to go to sleep as there will be a delay in between taking it and achieving the beneficial effect. It can be a problem if the baclofen wears off overnight.

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**Karen:** I have constant burning pain which is mostly in my arms. I have had this for approximately four years. It started when I had a nasty relapse. We have tried loads of different medications eg pregabalin (Lyrica), gabapentin, amitriptyline, oxcarbazepine, carbamazepine (Tegretol), Versatis lidocaine patches but nothing works... My GP is unable to prescribe me Sativex to try. The pain is constant and varies from 6/10 to 9/10 on a really bad day. Do you have any recommendations?

**Dr Ilan Liebman:** You are describing neuropathic pain. Going back to basics, the first question to ask is, have the trials of the medications been appropriate? And I mean by that, what doses and combinations were tried?

I often see patients who have not been taken to the optimal therapeutic dose of a drug or been tried on combination therapies of chemicals with different methods of action. I suspect that I will be asked this question several times today so bear with me and I will commit myself to the regime that I tend to try, but clearly this

is a generic approach that needs to be tailored to the individual patient (size, weight, allergy, previous medical history, substance addiction, work etc)

OK here goes - neuropathic pain

I start with gabapentin. The maxim is start low go slow

100mg - day 1

100mg twice a day - day 2

100 three times daily - day 3

Then I add in 100mg each day until the MINIMUM therapeutic dose is reached of 300mg three times a day

I would then take someone up to a maximum of around 3.2g per day.

What dose did you reach, Karen?

**Karen:** I got up to the maximum permitted dose for all medications with the exception of oxcarbazepine, where I had extreme sickness as a side effect which resulted in weight loss and my MS nurse decided that it was better to stop taking it. I still take the maximum dose of pregabalin as it just takes the edge off of the pain but never gets rid of it

**Dr Ilan Liebman:** If the patient doesn't respond or bumps into side effect issues, I swap to pregabalin. Again, start low go slow

25mg twice a day - week 1

50mg twice a day - week 2

75mg twice a day - week 3

100mg twice a day - week 4

It is unusual to see absolutely no effect with neuropathic pain and one of the drugs to the maximum dose. Pregabalin can go up to about 300mg twice a day.

The next thing that I do is add in an adjuvant molecule (polypharmacy).

Adjuvants are drugs that may increase the efficacy of other drugs when given at the same time.

Usually, for no evidence based reason, I go for duloxetine 30mg once daily in week 1 and 2 then 60mg once daily thereafter.

I would also consider adding in an opioid. There is reasonable evidence that opioids plus anticonvulsants are synergistic (work together). The opioid to choose is really irrelevant as the side effects are very patient related. I usually start with morphine (Oramorph) 10mg twice a day and take it from there, but other compounds such as fentanyl patches, buprenorphine patches oxycodone, etc are all reasonable things to add in.

**Karen:** Again I got up to the maximum dosage the GP and neurologist would allow me to take and I stayed on this for about six months. The burning did not subside. I take 600mg of pregabalin a day. I have kept a pain diary for several months for my MS nurse to see if there is any pattern. The burning is worse when I try to carry out regular day to day tasks, such as work and general household chores

**Dr Ilan Liebman:** If all of the above fails then its time to try slightly more exotic chemicals:

- nabilone 1mg once a day in week 1 and 2 followed by 2mg thereafter
- ketamine, sublingual (under the tongue) beginning at 10mg twice or three times a day building up to 20mg three times a day (but get the 50 or 100mg

per ml solution as the bioavailability is better than the 10mg per ml oral solution)

- nortriptyline at night up to 50mg one to two hours before intended sleep time is also a staple

**Dr David Rog - neurologist:** I would broadly agree with Ilan, although I don't find that people who fail to respond to gabapentin find pregabalin helpful. The two drugs are very similar in terms of their effects but pregabalin is said to have a more predictable response and only needs to be taken twice instead of three times a day.

Ilan's comment about SLOW increase and ADEQUATE doses is crucial before abandoning a drug.

It's important not to underestimate the value of a good nights sleep. If you waken because of spasms or needing to get to the loo for example, discuss the optimal management of these disruptions to your sleep with your MS nurse, neurologist or GP. If you sleep well you may find that your other symptoms of MS, including pain, are easier to deal with.

Also I would encourage anyone who has tried several painkillers without success to ask to be referred to their local pain service who should take a more holistic approach to pain relief and management.

**Dr Ilan Liebeman:** I agree with your comments on gabapentin vs pregabalin. The only reason I always try is that the occasional responder. It would be a shame to miss given the refractory nature of the problem in many instances

**Dr David Rog - neurologist:** It's also important to have realistic expectations as to what treatment 'success' is in managing neuropathic pain. Although we wish to completely relieve nerve pain, realistically at present a success is to reduce the level of pain, ideally to the point that you can put it to the back of your mind and get on with your daily routine.

**Dr Ilan Liebeman:** With regard to 'success', absolutely David. I think that expectation has a deal to do with sensible trials of the medications. I think unfortunately that we may not push doses adequately or remain on medication appropriately because our expectation of what can be achieved is unrealistic

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**Janette:** My feet feel either totally frozen or burning hot. At times one foot can be frozen while the other is hot. They are so hot through the night that I am wakened and can't get back to sleep until I get them cooled down enough. I take gabapentin but it doesn't seem to be helping. Any advice would be welcome.

**Kate - MS nurse:** What dose gabapentin do you take and how long have you taken it for?

**Dr Ilan Liebeman:** It's either a peripheral or central neuropathic pain. Either way, currently the pharmacological response is the same. Have a look back on what I have said re pharmacological management of neuropathic pain. The temperature changes will also be related to autonomic nervous system (ANS) dysfunction. The ANS that controls blood flow and so regulates the limb temperature.

**Kate:** I have the same experiences with my feet as Janette. I felt that there was something non-MS going on with my feet and something that was secondary and caused by MS. After asking for over five years, last Monday I had a home visit from a chiroprapist who gave me excellent explanations of all the foot problems. The part that is relevant to the burning sensations was to do with the capillaries - blood not getting in and then rushing in and not getting out - and something to do with the "wastes" that had accumulated whilst the feet were cold. Getting clear about the non-MS part of the pains in my feet will help me manage it better. When things get bad it triggers spasms and rigidity which are very painful and affect my hips

**Dr Ilan Liebeman:** Sorry Kate, but that explanation wouldn't fit into my model of neuroscience or medical understanding. I don't buy into 'wastes accumulating with cold feet'. It sounds much more like a dysfunction of the autonomic nervous system or a resistant central or peripheral neuropathic pain

**Kate:** Yes, it will be a dysfunction of whatever triggers the blood vessels to constrict and open, and so if circulation get affected then presumably the normal blood functions can't be so good. And the burning and itching is the result of that. Sorry I can't be technical, but at 2am when you feet are driving you mad there is no one to give advice. Cooling them, raising them and massaging my calf muscles all seem to help

**Dr Ilan Liebeman:** Burning and itching is maybe a sign of a centrally mediated pain. You feel it in your feet but the dysfunction of the nervous system causing you to have that experience may be much higher up in the nervous system

**Simon - MS Trust:** We will also have a physiotherapist online later and she might have more thoughts on some of the physical things that can be done to reduce the effects of pain

**Kate:** Thanks Simon. I'll try and come back then. I'm interested in what causes the types of hot/cold/burning sensations in feet. How does one determine whether it is a local problem or a centrally mediated pain? I think the local pain gets 'amplified' because of MS damage.

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**Julie:** I too have pain in many places, largely in legs - particularly bad in the back of my thighs - and also in my back and arms. Like Karen I have tried many medications and none work at all and have diabolical side effects like really severe constipation and also drying of the eyes etc. I would really appreciate information on any new painkillers which might actually work plus don't have side effects!

**Dr Ilan Liebeman:** It can be a real challenge to find this. With regards to opioids, my feeling is that much of the side effect is dose related. By this I mean that if you are the sort of person that gets constipated with opioids then all of them will do it too you at dose equivalents and so the best thing to do is to try different routes of administration, particularly patches as opposed to oral medications.

There is a new opioid that has just been launched called Targinact, which is a combination of Oxycontin (an opioid) and naloxone (an opioid blocker). The idea being that the naloxone blocks the gut receptors that mediate constipation. I haven't yet had the opportunity to prescribe enough to see if the marketing hype translates into the actual clinical world

**Julie:** Thanks for that ... might this possibly also help on the dry-eye side effect as well? BuTrans (buprenorphine) had a terribly drying effect so had to be stopped

**Dr Ilan Liebeman:** On the subject of newer molecules and approaches, I am aware of a high strength capsaicin patch that is apparently applied in hospital (not sure why) for about 30 minutes and then apparently gives up to three months of relief. They are in focus group stage for the marketing of it in the UK. David do you know any more about this? I am also aware of the development of a bupivacaine based patch but that is a couple of years away from launch

**Dr David Rog - neurologist:** I don't know about the higher strength capsaicin patch. Presumably it would cause even more intense burning whilst the substance P is depleted?

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**Robin:** I take a wide variety of pain relieving drugs for neuropathic and muscular pain and spasms. In consultation with my GP, neurologist and MS nurse we often review dosages to determine both need and dose level to try to minimise use as I currently take 19-23 pills daily.

What is your view of the benefits of yoga prior to bedtime to try to relax muscles as far as possible, to try and reduce the ever changing and exciting variety of pains, cramps, spasms, hot heels, body twitching etc. that I have the pleasure of experiencing each night even with very high levels of muscle relaxants and pain relief medications I take?

**Dr Ilan Liebeman:** Yoga has got to be excellent for reducing the stress response to pain and reducing the inevitable amount of adrenalin that is being pushed out as you experience pain. The same goes for learning a set relaxation and deep breathing routine for when you wake with pain, spasm or other dysastheasias at night

**Kate:** I agree - yoga and breathing routines are excellent. I'm lucky to have a yoga/shiatsu therapist visit once a month. Makes a big difference and he also does some specific work to keep my hips from getting out of alignment, which I think is caused by spasms/rigidity

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**Karen:** I am in the process of getting a referral to a pain clinic but not sure what they will be able to offer me that we haven't tried already.

**Dr Ilan Liebeman:** What can a pain clinic offer? It depends primarily on what facilities the clinic has. I am not trying to dodge the issue here, but facility and resource vary hugely across the country and there is no equality of access. Some clinics are hugely medically interventionally biased and some very, very cognitively biased. The best tread a middle road - as ever in life

The gold standard as far as I am concerned is:

1. Getting seen in a reasonable time frame and being able to communicate with the service when you aren't in the outpatient clinic but at home (the service has a phone line that is responded to)

2. You get to see someone for a reasonable period of time (between 40 minutes and an hour) at the first or second attendance and get the time and opportunity to go through your pain issues and problems
3. The clinicians go over the various pain issues and areas and ensure that the diagnosis and explanation given to you has been adequate and correct
4. They take the time to go through the medications you have tried and make sure that the trials have been appropriate
5. They consider the various approaches of polypharmacy (taking more than one drug at once to increase the effect of treatment)
6. The clinic may be able to offer interventional therapies unavailable in the community such as sequential lidocaine infusions or, dare I mention it, Sativex prescriptions
7. The lifetime incidence of spinal pain in the 'healthy' population is 80%, so access to the management of non MS related chronic musculoskeletal pains is clearly an advantage
8. The better clinics have an opioid service that monitors opioid prescriptions and rotates medications around to try and get over side effect issues
9. Psychological support and therapy are offered, either on an individual basis or through group based cognitive behavioural therapy on pain management programs
10. Specialist physiotherapy is offered access for rehabilitation exercises and pain management
11. A TENS services is available
12. Acupuncture is available
13. Medication review clinics are offered
14. I've probably forgotten something but there we go

**Dr David Rog - neurologist:** I think in practical terms a pain clinic should offer the patient more than just tablets! I agree with Ilan (who runs a very good pain clinic) that they do vary in approach and facilities. So Karen I think it would be reasonable for you to ask to be referred to a pain clinic.

**Karen:** Thank you, let's hope the waiting list for my local pain clinic is not too long as the burning is driving me crazy

**Dr Ilan Liebeman:** My view would be that for someone with a significant refractory problem, a referral to a pain clinic is always reasonable, as long as expectation is not unreasonably hyped. In my view, either the fact that nothing more can currently be achieved can be reaffirmed by an independent and detached clinician, who can then have the time and resource to help someone try and cope or a new set of eyes and ears may have the resource or train of thought to begin a helpful therapy

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**Simon - MS Trust:** Someone mentioned living in areas without easy access to specialist pain services. The charity Pain Concern contacted us in advance and asked us to point out that NICE are publishing their draft guidance on *Pharmacological Management of Neuropathic Pain in Non Specialist Settings* on 14 October and that it is important to get as many people as possible commenting on this draft (see the NICE website at <http://tinyurl.com/nice-pain>)

**Dr Ilan Liebeman:** Please do comment all of you that can. The more people that contact them and make their concerns clear the more likely that sensible guidance may be generated.

I was tempted to share with you all my views on NICE - suffice to say I am not a great fan of un-elected and effectively unaccountable quangos... not my sort of democracy. So, enough said, all please write in and raise the issues that you have. Enough of the soap box!

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**Steve S:** Hi, I know this is a bit off topic but I am on Rebif 44mg and have started to get injection site lumps and itching, red marks, etc. I'm rotating sites but just wondered if there was anything else I could do?

**Dr David Rog - neurologist:** Simply speak to your MS nurse. She (or he) will go into things in more detail and if necessary observe your injection technique which may have altered since you first started. It's a bit like bad habits you pick up after your driving test. Unfortunately some people persist in having injection site reactions despite our best efforts...

**Steve S:** Thanks David, wilco :-)

**Kate - MS nurse:** Some injection site reactions simply cannot be avoided completely, but your MS nurse should be checking them regularly. Heat or cold packs can sometimes help, as can aloe vera or witch hazel gel gently applied post injection

**Steve S:** Cool, thanks Kate

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**Paddy (my husband):** Paddy has a constant pricking sensation to his face which is getting unbearable. Any other medication suggestions would be very welcome.

**Kate - MS nurse:** Is he on any meds for trigeminal neuralgia? Tegretol (carbamazepine) is usually quite effective. Has he discussed this with his neurologist?

**Paddy (my husband):** The medications he has tried are (excuse the spelling) lamotrigine, sodium valproate (Epilim), pregabalin, gabapentin, carbamazepin, Tomarite, nabilone, methadone, lidocaine gel, buprenorphine patch, naltrexone.

**Dr David Rog - neurologist:** It's important to make sure the diagnosis of trigeminal neuralgia is correct as I see a lot of people who are labelled with this. I would suggest they consult their local neurologist who should assess them carefully.

**Dr Ilan Liebman:** If it's true trigeminal neuralgia (lancing pain lasting a few seconds to a few minutes and then resolving completely) then I suggest that an MRTA and referral to a neurosurgeon who would be prepared to decompress is appropriate.

Trigeminal neuropathy is pain in the same area which last much longer and is semi permanent. This type of pain responds poorly to decompression unfortunately.

Decompression for true trigeminal neuralgia in MS patients also is not as successful as in non MS related individuals, however is still undertaken. But I may be out of date on this as its a while since I referred someone to a neurosurgeon for this

**Steve:** Sorry, what is MRTA?

**Dr Ilan Liebeman:** Magnetic resonance tomographic angiography. It's an MRI with dye

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**David:** I have had pain in my legs continually now since beginning of the year. I have tightness in my calf muscles and my legs feel weaker with walking. It is becoming more and more of an effort to climb stairs. I don't have any respite from the pain/stiffness in my legs and walking gets harder for me. Is this likely to improve?

I was diagnosed with relapsing/remitting MS, but my symptoms now persist and are getting worse without any remission period. I also have problems with pain in face and pain in ear

**Kate - MS nurse:** Was this episode diagnosed as a relapse when it started? Did all these symptoms start at the same time? Were you treated with steroids at the time?

If it is a relapse then you should see some degree of recovery, but difficult to know for sure. Baclofen may help with the tightness in calf muscles and it may be an idea for a physiotherapist and/or occupational therapist to look at the leg weakness and suggest exercise/advice re maintaining strength/additional aids etc

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**Gillian:** I wonder if anyone can relate to my experience and share what, if anything, might help. A sudden relapse three years ago has left me with a severe crushing pain on the left hand side of my body, but in particular in my head. I liken it to an inner skin which is constantly shrinking around the brain.

I have tried gabapentin, pregabalin (Lyrica), amitriptyline and am currently on nortriptyline. Acupuncture, a TENS machine, massage and physiotherapy have brought no relief. Most of the drugs interfere too much with my cognitive skills and ability to remain alert at work and when driving, and cannot therefore be taken at a level to deal properly with the pain. I resort mainly to distraction to try and escape the continual 'crush' by being involved with anything and everything around me. This of course only works until the inevitable fatigue sets in. Any suggestions?

**Dr Ilan Liebeman:** Sounds like a central neuropathic pain. For management I refer back to my previous comments on neuropathic pain management. Assuming the trails of drugs you have been on have been appropriate and polypharmacy has failed, then I would consider trying nabilone. It's an off license indication but worth a go

**Kate - MS nurse:** Are you being seen by a pain specialist? I'm guessing you are. It sounds really hard for you and I think you are doing a lot of what you can already. Would the pain be bearable if it wasn't for the fatigue, and if so how do you currently manage your fatigue? Maybe the being constantly involved with anything and everything is in fact triggering the fatigue, but I understand the need for the distraction also

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**Bernice:** I have constant pain in my arms, legs and back. I have trouble with my hands going numb when driving a car. Also pains that generate from mid stomach area all the way down and out through the pelvic area. Sometimes it brings me almost to my knees. It last for a few minutes and goes away. Any suggestions?

**Dr Ilan Liebeman:** It's very difficult to answer the question directly and this reply I suppose is directed to all such questions. The answer for suggestions really depends on what has been tried already and the underlying diagnosis of the issue presenting. Not all painful symptoms are MS related and so new issues and problems must be looked at to ensure unrelated pathology is picked up. Once that has been done, then the best thing to do in my opinion is to go back through the basics of neuropathic pain management and reassure oneself and the patient that appropriate trials of drugs and drug combinations have been done. And at the same time get a referral to a specialist who is comfortable using molecules off licence and a poly-pharmaceutical approach as well as accessing clinical psychology for help with psychological approaches to managing stressful pain experiences

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**Robin:** In addition to my 75 fentanyl patches, baclofen etc, I have at times used oramorph for breakthrough pain. I have now stopped using oramorph as it removes any ability to think and often use tramadol. With prolonged use of tramadol does the body build up an immunity to it and therefore reduce its effect?

**Dr Ilan Liebeman:** Immunity is the wrong model - tolerance is a better concept, and yes tolerance can occur. The way to deal with tolerance if it occurs is to swap molecules and give yourself a tramadol holiday. The other thing to do is make sure you are on the lowest acceptable dose and so give yourself room for dose elevation

**Robin:** Thank you. I will build in the ability for dose elevation. This should also help my cognitive function as I have significant short term memory problems and regularly see my memory consultant. There is an amazing array of physical cognitive support tools such as memory watches, which have helped me a great deal

**Simon - MS Trust:** Have you seen the StayingSmart - [www.stayingsmart.org.uk](http://www.stayingsmart.org.uk) - website? It's a tool we've helped develop for people with cognitive symptoms.

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**Geoff:** Are pain and fatigue linked? I get odd feelings in my arms - burning, crawling feelings - and these seem to be worse when I fatigue is worse

**Dr Ilan Liebeman:** Yes, they are linked. The chemicals that mediated pain transmission are the same ones that mediate mood. Fatigue alters mood and hence pain. Fatigue also alters somatic awareness and this also affects pain experience. Lost sleep and chronic fatigue are correlated with increased pain experience in fibromyalgia and there is school of thought that suggests that it is the sleep disturbance that is a primary driver in the pathogenesis of fibro

**Vicki - MS nurse:** It is important when trying tackle pain and fatigue in MS to remember a couple of other things:

- low mood or depression will 'amplify' pain very much

- the best benefit will be gained from using a range of strategies not just medication alone - you will get more 'bangs for your bucks'
- 

**Dave:** I have what I can only describe as a shrivelling-up feeling in my feet and legs that appears as the day progresses. It lasts for a while and then subsides. Some days are worse than others. It is like my feet and calves want to curl up inside themselves and, while not excruciating, is extremely unpleasant. I do find that getting up and walking about relieves this pain somewhat, as does jiggling my feet around if I am sitting down. I have also noticed this pain in periods where I have had involuntary movements in my calf muscles (rolling and twitching). Am I describing neuropathic pain here? Someone once suggested I might have 'restless legs' - not quite sure what they meant.

**Geoff:** The feelings I get in my arms probably fit that idea. Not painful in themselves, but unpleasant and distracting and wear you down after a while

**Simon - MS Trust:** As movement seems to help, maybe this is something you might want to put to Linda Miller, an MS physiotherapist who will be online later in the day

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**Gemma:** I have had pain in back of my thigh for weeks now. It was certain ways I moved it that made it sore - it's not a pain that is there all the time just when I move it certain ways. Sometimes walking up stairs can be sore on my thigh. Some days my thigh isn't that bad, other days it can be quite sore. It is underneath my thigh where the pain is.

**Dr Ilan Liebeman:** Gemma, get someone to check this isn't a sciatic type pain from a disc or nerve entrapment

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**Dave:** I was diagnosed in 2004 and have had constant neuropathic pain from my neck all down the right side of my body. I currently take 150mg of pregabalin in the morning and 300mg at night. I am constantly waking in the night with pins and needles and numbness in both arms and hands. During the day, as fatigue starts to kick in, my right legs feels like cold water is running down it. Any suggestions please.

**Dr Ilan Liebeman:** Hi Dave. As I said earlier to Bernice, it's very difficult to answer the question directly. The answer depends on what has been tried already and the underlying diagnosis of the issue. Not all painful symptoms are MS related and so new issues and problems must be looked at to ensure that unrelated causes are picked up. Once that has been done, go back through the basics of pain management and reassure oneself that appropriate trials of drugs and drug combinations have been done. It is also important to get a referral to a specialist who is comfortable using molecules off licence and a poly-pharmaceutical approach. It is also helpful to access clinical psychology for help with psychological approaches to managing stressful pain experience

**Dave:** Thank you for your suggestions. I am seeing my neurologist next month I will show him your suggestions

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**Geoff:** It always fascinates me how people describe pain. I would say mine is crawling, Dave said 'cold water', other have said pins and needles and so on. It's difficult to pin down such a personal thing when trying to describe it, isn't it?

**Dave:** I totally agree - we each have our own MS. What we need is MS dictionary we could all refer to!

**Dr Ilan Liebeman:** Burning, itching, water down the leg, ants crawling under the skin, pins and needles - these are descriptions of either painful symptoms or dysaesthesiae (unpleasant sensations) that are, if not pathognomonic, used very frequently of a description of neuropathic pain be it peripherally (in the extremities) or centrally (in the brain or parts of the cord) mediated.

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**Geoff:** Are there approaches to pain that don't use drugs? If so, are these add-ons to medication or are there things that might help in their own right?

**Dave:** I have tried TENS, yoga and tai chi but they did nothing for me, so I guess drugs are all that's left. Or are they?

**Dr Ilan Liebeman:** Non drug related approaches include psychology - individual or group, acupuncture (best for musculoskeletal pain). TENS, yoga, or any other relaxation technique that helps reduce the adrenalin response (flight or fight) to pain

**Ben:** I've tried a couple of complementary therapies (acupuncture, herbal remedies) but they didn't help in my case. I think my pain condition is too far down the road. I prefer to rely on medication nowadays to be honest.

**Jen:** My experience is that they provide a bit of short term relief (which is much appreciated) but the effects don't last long

**Linda - MS physiotherapist:** I think you are right, Ben. Where pain is severe people shouldn't rely on complementary therapies but may get additional help from them. There is an issue that most of these therapies need to be ongoing or at least topped up from time to time. TENS is something that can be used very successfully in addition to medication for many different types of pain. Has anyone had any experience from using TENS?

**Vicki - MS nurse:** As Linda says they are part of the range of resources to manage pain etc. they can often mean that orthodox medication can be more effective at lower doses because people are more physically relaxed and receptive to analgesia

**Ben:** Your work sounds so vital, Linda and I'm sure it's appreciated. It's hard to remain positive sometimes with chronic pain, but I think that is important as well. It is for me, anyway.

**Bill:** I agree with Ben. Pain can be so draining. Other symptoms can provide their own hurdles, but pain is the one that can sometimes gnaw away at you

**Linda - MS physiotherapist:** It is so important to try and remain positive and for that you need support and understanding from family, friends as well as from a range of health professionals. Mood and pain are linked in a very complex way. It sounds as though you are aware of this and doing your best to keep your spirits up!

**Vicki - MS nurse:** Pain is so very draining Bill. You cannot live a life when it is filled with pain. What happens then is the physical pain gets fed by feeling psychologically down and then life becomes more limited and the pain becomes a bigger 'noise' in a much reduced life. If any of you feel this is the case it is important to get this sorted out by a team of experts who can bring different solutions.

**Ben:** The BBC did a great 'Medical Matters' pain podcast. It's not on the BBC website anymore sadly.

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**Elaine:** I have constant pain in the soles of my feet. It is like walking on crushed glass. Also MS hug on right side. I am taking 900mg pregabalin a day and 20mg oxycontin a day. Recently I tried amitriptyline and duloxetine but could not tolerate the side effects. I have had optic neuritis since losing sight completely in February 2005. Any suggestions on pain control?

**Dr Ilan Liebman:** As I mentioned earlier, if the standard approaches fail then its time to try other approaches such as:

- nabilone 1mg once a day in week 1 and 2 followed by 2mg thereafter
- ketamine, sublingual (under the tongue) beginning at 10mg twice or three times a day building up to 20mg three times a day (but get the 50 or 100mg per ml solution as the bioavailability is better than the 10mg per ml oral solution)
- lidocaine infusions

Also read my previous posts to Bernice and Dave - the doctor should assess the symptom to identify and treat any unrelated causes. Once that has been done, go back through the basics of neuropathic pain management and check that appropriate trials of drugs and drug combinations have been done. It is important to get a referral to pain specialists comfortable with using the range of medications available and also exploring psychological approaches to managing stressful pain experience

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**Carol:** Hi I had a big (first, I thought at time) relapse in June. I was diagnosed with relapsing/remitting MS in August. I've been off work since June and still feel aches in arms, back and legs. I am very weak and feel no strength in my body though my brain's lot better. I have improved overall but very slowly and wonder when I will feel as I did or is this it?

**Kate - MS nurse:** It is very early days in terms of recovery from your relapse. It can take several months (approx 3-6) to recover to your full potential. It is difficult to predict your degree of recovery, but usually recovery is good. Were you treated with steroids at the time? These can help to speed recovery up a little although eventual outcome will be same with or without

**Carol:** Yes, I was put on steroid drip for three nights as I collapsed in hospital and couldn't move. Would another dose of steroids give me the extra boost to give me the oomph to get back to my self or is my body healing? It was long relapse, which I didn't know at the time, and lots of things went wrong - vision, coordination, brain, balance etc etc

**Kate - MS nurse:** Glad you had course of steroids. Another course would not necessarily be indicated. You are right, your body is healing, and depending on

how severe the relapse was, this will affect the amount of time for you to recover. Try to be patient, keep doing what you can and give yourself chance to recover

**Carol:** Thank you, Kate. It all came as a big shock and am trying to deal with it and find out as much as I can.

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**Bill:** Just reading back and what Dr Lieberman has said about checking things are MS is very true. I've had a GP who assigned everything to my MS but sometimes this has turned out not to be the case. He also suggested paracetamol for a pain that turned out to be neuropathic and I now know that that approach is no help at all.

**Dr Ilan Liebeman:** Thanks Bill :-)

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**Steve:** Do you have thoughts on the role of cannabis and Sativex in treating pain?

**Dr Ilan Liebeman:** I answer this with trepidation. I prescribe Sativex on a named patient basis to a handful of individuals currently, for a variety of indications, most not MS related. I have had no success in getting the PCT to take over the scripts however I am ever hopeful.

I believe that Sativex is possibly being submitted for approval for spasticity related to MS but not pain in the near future - our lips to good Lord's ears as they say... If anyone knows more about this please post.

My experience to date is that Sativex is like every other drug I have prescribed for chronic pain - fantastic for a few, good for some if not many and useless for many. Side effects seem to be mainly cognitive and sedative - but certainly less than for opioids and anticonvulsants. But bear in mind my prescription experience is limited to about 25 patients not the thousands for the other medications that I more commonly use.

Re: cannabis. This is hugely emotive area because of the largely irrational and prejudiced approach (in both directions) that is taken in the discussion. Cannabis is illegal in the UK and I would never ever encourage someone to break the law, so let's frame this discussion with reference to a hypothetical discussion in a scenario where one was in a country or place where its consumption was legal.

Cannabis has been shown to have very nasty effects on the developing brain and it is associated with the incidence of schizophrenia as well as a variety of other psychiatric illnesses. Regular consumers of large doses frequently describe feelings of paranoia, anxiety, mood swings, emotional change, erectile dysfunction and a large list of other cognitive effects. Its clearly hugely dangerous to the developing brain and as far as I am concerned (ie in relation to its deliberate sale and marketing to anyone under 21 or whenever the neuroscientists feel the brain has developed) in that regard should be treated as a class A drug.

Consumption by adults of cannabinoids from whatever source in the management of non malignant or malignant pain is an entirely different issue and in my view needs to be taken strictly on a risk benefit analysis. Clearly the trials for Sativex have not persuaded the regulatory authorities of its efficacy in MS related pain in

this country yet but that may change. The case is different elsewhere, for instance in Canada.

At a physiological level, there is no doubt whatsoever that there is a significant input of the endocannabinoid system to pain modulation. On this basis, a therapeutic trial of cannabis might seem a logical approach if one cannot access Sativex. Never forget however that smoking is bad for you and this is the main route of administration for cannabis, although its oral bioavailability (how much therapeutically active drug gets into the system) is apparently good.

The troublesome thing with the endocannabinoid discussion is that the very large body of anecdotal evidence is in some terms rather positive and medicine to date has been pretty feeble in delivering reliable and hugely effective analgesics for MS related neuropathic pain.

So... my final comment on cannabis is as follows.

If one was in a situation that allowed legal access (which is clearly not the case in the UK), one should treat it like any other drug and use it sensibly, balancing the effect, side effect and risk profile. Reliable dosage will also be an issue as it is not going to come as a quality controlled tablet.

**Vicki - MS nurse:** The trials of Sativex are still ongoing. Like many new drugs and therapies; roughly about a third of people find it helpful, about a third say it doesn't help and another third feel worse.

Can I second Dr Lieberman's comments. We are still talking about a hypothetical situation in the UK and we are also talking about something that has significant risk attached for some patients or users.

**Steve:** Thanks for this full answer

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**Chris:** My partner has suffered from chronic pain which has spread rapidly recently throughout her body except her head and one arm. Her legs are now so painful, a walk of any distance is a great challenge. Until we find a drug that at least makes the pain bearable the overriding issue is pain management. We read of multi-disciplinary approaches to MS and neuro-rehabilitation services but these do not seem to be available to us in our area. It is horrible to witness the effect that pain has on my partner and any help/advice available out there will be very much appreciated.

**Cynthia:** I was prescribed amantadine for my fatigue, but three days after taking this my right leg became very stiff and feels like it is on fire. My feet have also become more like crumpled paper. I stopped taking the amantadine as per my MS nurse's instructions. Is this classed as a relapse?

**Dr Willy Notcutt:**

[Dr Notcutt, a Consultant in Pain Management in Great Yarmouth, was unable to take part in the chatroom but sent these general comments on pain management having seen some of the questions that were asked on the day]

I have read through all the pain stories provided by these 10 people. What quickly comes across is the characteristic variability of the pains and sensations described. It is only when one has heard many of these that it becomes possible to identify them as directly being due to the effects of MS causing nerve damage

and malfunction within the pain and sensory nervous system. Other pain may arise from spasms or spasticity, bladder dysfunction, or mechanical effects of weakened muscles. Unfortunately, it is usually difficult to further define the exact cause and its location.

With all chronic pain, particularly from nerve damage (neuropathic pain) it is impossible to predict what is going to be beneficial. It is not just the pain one is trying to ease, but also abnormal and unpleasant sensation. Improving sleep is a critical factor especially if it is disturbed because of pain. The value of this in helping the individual cope with his situation cannot be overestimated.

Whilst physical therapy may be helpful with the more mechanical and muscular pains, treatment is generally based on drug therapy. Unfortunately, almost all drugs have to get into the nervous system to exert their effect and hence patients can experience side effects.

The range of drugs commonly used are:

- Conventional simple analgesics (eg. paracetamol, codeine)
- Strong analgesics (eg morphine, oxycodone, methadone)
- Antidepressants (eg amitriptyline, nortriptyline, duloxetine)
- Anti-convulsants (gabapentin/pregabalin, carbamazepine)
- Anti-spasmodics (baclofen, tizanidine)
- Cannabinoids (Sativex –unlicensed, Nabilone)

None of these drugs (except the antispasmodics) are licensed for use in MS and very few clinical studies have been performed to direct the doctor in prescribing appropriately. Therefore their use depends on the experience of the clinician managing the patient. Treatment therefore becomes little more than trial and error.

Too many patients get fobbed off having presented their apparently 'bizarre' accounts of what they experience. Perhaps the most important thing then is to have a doctor who listens to the account of the symptoms, agrees that they are real and then works to try and achieve improvement. The latter can be hard work balancing benefit against side effect, in customizing the treatment regimes to the individual. However, having someone who is actively working to obtain symptom relief is of great help in itself.

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**Pat:** I get pain from my catheter. I have to go to a private hospital (luckily we have insurance) to have a bladder wash out every nine to twelve months. I also get pain in my feet and my legs due to the build up of fluid. On waking, or sometimes in the night, the spasms are so strong that I feel they could well break my legs.

**Vicki - MS nurse:** If someone gets spasm at night it can be made worse by the position in which they are lying. The best position is to have the knees slightly bent and slightly apart. Use a pillow (or two) to get a comfortable position like this. Sometimes a small dose of diazepam at night can help as well. If the catheter is a persistent source of pain it may be triggering the spasm as well. A suprapubic catheter is best for many people.

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**Carol:** I wanted to know what hurts Most of the disease modifying drugs - Rebif or Avonex. I think it will be one or other if get it

**Vicki - MS nurse:** If you get a really good injection technique there should be no significant discomfort or pain. The intramuscular injection (into a muscle) does not hurt because there are no pain receptors in the muscle fibres. The subcutaneous (under the skin) injection should not hurt if you carefully rotate the sites, use an injection device that is set correctly and the injection liquid is at body temperature and not too cold. Your MS nurse will take you carefully through the process.

**Carol:** Thanks Vicki. I need to make decision by Tuesday as I'm seeing the neurologist then. I'm thinking once a week get it over with, but was worried about muscle bit

**Vicki - MS nurse:** I have tried the muscular injection on myself. It does not hurt. Good luck and I hope you have a bottle of bubbly ready to celebrate when you start your treatment!

**Carol:** LOL. Thank you

**Simon - MS Trust:** Carol, have you seen the MS Decisions website - [www.msdecisions.org.uk](http://www.msdecisions.org.uk). This is an independent site set up to help people making this sort of decision. The MS Trust also does a book called *Disease modifying drug therapy*, which might also be some help (see the Resources section at the back of the transcript).

**Carol:** Yes, I have looked at that site. I know everyone's pain threshold is different but am hoping I can do Avonex once a week a week and can do it properly so it doesn't hurt too much.

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**Carol:** I want to look at yoga too as I have pretty constant backache but my balance is way off and I don't want to fall over

**Simon - MS Trust:** Linda Miller, a physiotherapist, will be online in short while. She might be able to suggest something in the yoga/exercise line that might help

**Carol:** Thank you

**Jude:** Carol, I know pain is different for everyone, but I have pain in my lower back and have seen a physio. She is hoping that a few sessions can help

**Carol:** Thanks Jude, hope so. I'm still learning, as we all are. I just want to feel normal again but not sure if that happens

**Vicki - MS nurse:** People with MS are at risk of postural related problems when they compensate for an area of weakness or loss of sensation. Sometimes they don't even know they have lost some of their sense of position and don't know they are getting into bad posture or movement habits. Bad back is potentially a sign of this. I recommend the new posture book

**Simon - MS Trust:** The posture book Vicki mentioned is *Are you sitting comfortably..?* (see Resources section at the end of the transcript). It was written for people who spend most of their time sitting and aims to offer practical

suggestions to improve posture and ward off the problems continued bad posture can cause

**Carol:** Sitting comfortably? Probably not. Slouching on sofa lol. I will see if I can get hold of copy, thanks

**Simon - MS Trust:** There's information about publications at the end of the transcript or visit the MS Trust website to read, order or download a copy. All of our books are free.

**Linda - MS physiotherapist:** Pilates is particularly helpful for people with balance difficulties and back problems. It might be that you have developed a 'frozen shoulder' and it would be worthwhile seeing your GP about this. He might refer you to a physiotherapist

**Jude:** My physio said my posture was bad because I was compensating. I asked my doctor to refer me to physio and it only took about a fortnight to get an appointment. I live in the north east so it seems that access is pretty good here judging from my experience

**Carol:** Thank you, I will do that. Also just this minute I booked an appointment with my GP, so I will ask for physio and see if he can get me an appointment. Thank you everyone for your help, it's great

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**Vicki - MS nurse:** I have just seen the results of a programme using horse riding (hippotherapy) to improve balance and stability for people with MS. It worked extremely well and also improved general well being. So, if any of you like horses, it is worth considering! It is always worth doing an activity you enjoy, such as pilates or yoga that will also bring these additional benefits.

**Dr Ilan Liebeman:** Re: hippo therapy, I would imagine that a wobble board will do much the same thing. Hopefully the physios will be able to comment on this

**Carol:** I loved riding years ago. I used to have my own horse when I had money and no bills lol, but I'm worried about falling off and the expense. I think they may think I am the hippo. Wobble board suits my description too ha ha. I would prefer the horse me thinks

**Linda - MS physiotherapist:** Both horse riding and working on a wobble board build up the core strength (muscles around the hips and pelvis), which can help improve balance, posture and lower back strength and stability. Just different ways of achieving a similar aim I suppose. It depends which one appeals to you more.

**Simon - MS Trust:** Our Open Door newsletter had an article on hippotherapy a few years ago, written by a physio in Glasgow (see Resources section at the end of the transcript).

**Carol:** Thanks for that, I will read it later. Just the thought of it has cheered me up

**Helen:** I was lucky enough to learn to ride and it was more fun than a wobble board! I find the riding and swimming helped my fatigue and neuropathic pain with help from amitriptyline 25mg at night and citalopram, along with pacing myself and not exhausting myself. Otherwise I can have days in bed with awful

facial pain and resting is the only way to get it under control. I have found the websites mentioned useful and great to have drug options and doses clearly explained

**Linda - MS physiotherapist:** Helen, thanks for your very helpful tips. I would agree that pain is very much exacerbated by 'overdoing things' and it is difficult sometimes to get the right balance.

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**Andy:** I am interested in how many people have access to palliative physiotherapy through the NHS. Hillingdon PCT have stopped all regular access for MS patients and this has had a detrimental effect on at least 40 people. NICE make all kinds of recommendations but these can be interpreted in so many different ways. The pain aspect of MS in my experience is greatly helped by 'gentle' physiotherapy, which has helped me. I am interested in help other parts of the country are offering.

**Vicki - MS nurse:** Physiotherapy is still somewhat variable around the UK but a lot of physiotherapists are now able to have more control of open access referral etc. Some local MS groups are also running their own exercise classes with a physiotherapist who is paid to do some sessions. This works well as the cost is spread and the courses become shared social events. Some are also using local gyms and trainers to run classes

**Simon - MS Trust:** Quite a few MS Therapy Centres offer physiotherapy at subsidised rates. MS Therapy Centres are local charities that offer a variety of non drug therapies for people with MS. There is a map of therapy centres on the MS Trust website (see the Resources section at the end of the transcript).

**Linda - MS physiotherapist:** In Scotland there are exercise referral schemes where your GP or local health professional can refer you to your local authority gyms/swimming pools for exercise. Although these are not MS specific they are often still very beneficial and appropriate for people with MS. There are often classes for people who are less able also. Was it some other type of physiotherapy you were talking about, Andy?

**Andy:** Thanks to everybody that replied to my physiotherapy question. The problem at the Alderbourne unit and Hillingdon PCT is that they replaced a bi-monthly MS physiotherapy session with an eight week course which, in my opinion, isn't fit for purpose. The MS Trust maps of nearby centres sadly do not include information as to whether they have the capacity to deal with 70 patients that the local health authority just abandoned. The nearest one to me in Harrow has been oversubscribed and full for the past 11 years.

The bi-monthly sessions that Hillingdon PCT stopped were useful and allowed the use of specialist equipment in the Alderbourne gym. The sessions had run for over seven years very successfully. I appreciate some people get great help from yoga and other exercise regimes, but those in this area are either expensive or of little use. The MS Society's input into this problem was to offer to help with a replacement group, they then turned green and ran away screaming when the cost of a physiotherapist and the cost of insurance became apparent.

It's been almost three years since the physiotherapy was withdrawn and my range of movement and general flexibility has diminished significantly. I now get pain in my right leg and knee as I find the muscle is locked and I can not straighten it after sitting. My neurologist muttered about Zanaflex (tizanidine)

last month but I am loathed to take such a hepato-toxic drug. From the various responses it seems an MS physiotherapy training course is a good idea.

**Simon - MS Trust:** I think you're right about the limited capacity of Therapy Centres to pick up NHS clinics. Not exactly the same but have you seen our book *Exercises for people with MS* and the exercise DVD *Move it for MS*? (see the Resources section at the end of the transcript)

**Andy:** Thank you Simon, yes I have them both. I have also found some help, especially with pain, using the tapping methods outlined by Meir Schneider in his handbook of self healing. I find this method useful for neck pain, which, as my wife tells me, is because I have such a big head...LOL

**Linda - MS physiotherapist:** Sorry to here about your problems accessing physiotherapy, Andy. Even if there was an offer from physiotherapy to instruct carers/relatives to help with some physiotherapy/stretching then this might be helpful. It doesn't always need a qualified physio to undertake the physiotherapy programme but does need a physio to assess and advice others to what's appropriate. Splints and positioning wedges can also prevent deformity and maintain range of movement.

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**Marie-Edmee:** My husband has pins and needles in both legs, which only become painful on standing up. Otherwise does not give him any problems when he is sitting down. He takes three amitriptyline tablets at night. It is also suppose to help with spasms, but after over two years of the medicine, it does not appear to make any difference. Is anyone in the same condition? Any suggestions? Also, for several months he has suffered from itches on arms and the top of his shoulder and has been recommended to use Eurax (crotamiton) cream.

**Vicki - MS nurse:** Your husband is experiencing pressure as pain. It is when the nerves get muddled and 'cross fire' the messages. This happens quite a lot in MS. Can I ask two things? What dose of amitriptyline is he on? Does the Eurax help - is there any skin rash or redness?

**Marie-Edmee:** Roger has three tablets of amitriptyline at night. Yes, Eurax helps a bit - his arms and shoulders are creamed twice a day. It helps but does not seem to really get any better.

**Linda - MS physiotherapist:** What I would say about your husband's pain is that if it only comes on when he is standing there may be a 'mechanical' element and it would be worth asking for a referral to a physiotherapist to see if there is any other cause of his leg pain. Sometimes referral from the lower back can cause similar symptoms. Not sure about the itching though - sorry

**Vicki - MS nurse:** Linda is right. It is important to exclude any mechanical source of the pain. Sometimes a nerve root can become squeezed or trapped and this can cause a problem that is not MS related

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**Mary:** I am a reflexologist and I have only treated one patient with MS - he had the progressive type. He said he found it helpful and his leg felt lighter, back slightly less painful and he felt good. I think the last was the most important one. Have people used complementary therapies to help with pain and how do Linda and Vicki have thoughts on how they fit into management of the symptom?

**Linda - MS physiotherapist:** There is some evidence that reflexology can help with some of the symptoms of MS, in particular bowel, bladder, pain, spasm and muscle stiffness, quality of sleep and quality of life. We are just about to start a study to look at the effect of reflexology on these very symptoms in people who are more disabled with MS

**Karen:** I have reflexology once every six to eight weeks. It definitely helps my sleep pattern and dulls the pain for a bit (goes from 8-9 out of 10 to 4-6 out of 10).

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**Kate:** I asked a question about cold/hot/itchy feet this morning, and about things that might give some relief in the middle of the night when they are driving me mad. Simon said physiotherapist might have some advice. I'd also be interested in her views on whether this is local, ie in my feet initially, or centrally mediated as Dr Leibeman was thinking

**Linda - MS physiotherapist:** Hi Kate. Do you get this sensation at any other time? Are there any skin changes in your feet/ (eg rash, dry skin etc)?

**Kate:** I mainly have problems later in the day, and it is worse from 10pm-2am. Have since received the letter from the chiropodist which says apices of both first big toes were purplish, this may indicate poor microcirculation

**Vicki - MS nurse:** I think the skin discoloration does mean poor circulation. Do you do any exercise or raise your feet for this problem?

**Linda - MS physiotherapist:** I had a look at the earlier conversation you had this morning. Sometimes with these sensations it is hard to say that there is one particular cause and it may in fact be a mixture of issues going on that are MS and non-MS related. Forgive me for repeating earlier scripts but have you tried any medication to relieve the symptoms? Using TENS prior to going to sleep can sometimes help for neuropathic pain also. Has your chiropodist suggested anything to help?

**Kate:** I use a chi machine generally twice a day for 15 minutes. Daytime rest with feet elevated. Pedals - varies could do more. Exercises from the physiotherapist were making a difference to muscle strength in my legs but recently this has been difficult due to pain in my feet

**Bill:** Hi Kate. What's a chi machine? I've not come across that before

**Kate:** Bill, there is info about chi machines on [www.surgeofchi.com](http://www.surgeofchi.com)

**Bill:** Thanks, I'll have a look

**Linda - MS physiotherapist:** Kate, it does sound as though there is more than one problem here and more than one type of pain. How have you responded to any medication that has been prescribed so far?

**Kate:** I doubt there is one cause, but what I want to do is eliminate any that are not MS that can be dealt with. I have found it difficult to have discussions about non MS things. I know MS amplifies normal pain, and had proof when I dropped something on my foot. The response was out of all proportion and it took me a while to get the foot back on the floor. Luckily I did not fall. No suggestions have been made about poor microcirculation

**Vicki - MS nurse:** Sometimes people with MS can have problems with something called the autonomic nervous system. This is the system that deals with sweating, digestion, dilation of blood vessels and lots of things that are not under our conscious control. This may be the case with circulation in your feet.

**Linda - MS physiotherapist:** It might be easier to try and treat the MS pain with appropriate medication to see how much of your overall pain is relieved by this. That might give you a clearer picture of what is left and how that might be managed. I hope that make sense to you? TENS would be worth trying prior to going to bed for a minimum of an hour also

**Kate:** I'm not on any medication. When I ask about side effects they seem worse than the pain, eg dizziness and things affecting guts and bowels. There has been constant low level pain and painful sensations for a number of years now, and when I was having severe head pain I was not offered anything

**Linda - MS physiotherapist:** It is worth reconsidering trying medication for neuropathic pain. Amitriptyline can be taken before going to bed which might suit your type of pain. Gabapentin is generally better tolerated although there is a wide variation in response to any kind of medication and they all have side effects (although most people don't suffer from them). It would be worth discussing with your GP, MS nurse, consultant or neurologist.

**Janie:** What I wanted to say though is that 18 months ago before being diagnosed I was diagnosed as having plantar fasciitis in my left foot. Had lots of different treatments. Eventually diagnosed with MS, the foot specialist came to the conclusion that there was nothing wrong with my foot at all, and that it was my MS.

I get extreme pain in my heel and surrounding area of my foot. It can last for days or just five minutes periodically throughout the day. I never know from day to day what it's going to be like. One thing I do know is that if I have a good day, and I go out shopping for a couple of hours I do end up paying for it later that evening and the next few days. But what I find strange is that the pain can also move from day to day around the heel area, it might be on the back of the heel one day and the next on the left side travelling up the leg and the next on the right travelling all round the heel.

**Jude:** I also get pain in my feet it starts late afternoon and one of my feet feels as though it is swollen. Stretching it out doesn't help and can lead to spasms in my leg

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**Roy:** I have severe neuropathic pain behind both legs - calf muscles, thighs, all of backside and private parts. It's absolute murder to sit down and sometimes makes my eyes water with the intense stinging pain, which never goes. I play around with cushions to ease the pain. I also have numbness and loss of sensation in these areas. My medication is pregabalin 225mg three times a day,

tegretol 200mg slow release once a day. Ordinary pain killers are no use for my symptoms. I am 69 and have progressive MS

**Linda - MS physiotherapist:** Provided you are not experiencing any side effects from pregabalin, you could discuss increasing the dose further with your GP as you are not on the maximum dose. Your pain does sound a little unusual - 'intense stinging'. It is always important to preclude other possible sources of pain

**Vicki - MS nurse:** I agree with Linda's point about pregabalin. Dose response and tolerability varies hugely in people and some go beyond what is the usual maximum dose. Always start 'low and slow'. Roy's is an unusual presentation. It is important to always check for any skin rash or irritation that might be acting as a focus or stimulus for the pain

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**Ben:** Does anyone have suggestions about how partners, family and friends cope with their chronic pain? It's so difficult to explain sometimes what continual pain is actually like, and this can lead to difficulties

**Vicki - MS nurse:** Have you tried to draw the pain? Create a picture of it for everyone. Trying to describe neuropathic pain is almost impossible isn't it? Try different images to convey just what you are having to go through

**Simon - MS Trust:** There is a charity called Pain Concern for people experience pain (of whatever cause, not just MS). You can find them at [www.painconcern.org.uk](http://www.painconcern.org.uk)

**Vicki - MS nurse:** I often say to patients when they struggle to express their pain or discomfort to others that if I were to turn them inside out and everyone could see the scarring and inflammation on their nerves on the outside they would all be staggered and admire their ability to cope!

**Ben:** That's a good idea, Vicki. I have thought of writing it down but it sounds a bit gruesome even to me so I have been put off the idea a bit up to now! After ten or more years of neuropathic pain and peripheral neuropathy I have found a few coping strategies, the main one being, give yourself a break sometimes and go to bed to lie down/get some proper sleep when ever possible (I think this has been discussed earlier)

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**John:** A couple of questions:

1 - Why do I get hot legs, yet outside to anyone they feel cool including myself?

I am on gabapentin 300mg per day

2 - I am awakened most nights by a spasmodic pain in my right leg, which goes if I go to the loo for waterworks. Here again I am on 50mg of amitriptyline, and doxazosin (one in the morning and one in the evening). Sometimes I cannot go, which means that I am up the rest of the night.

**Vicki - MS nurse:** The 'hot inside' legs that feel cool are due to mixed messages in the nerve fibres. They are processing the sensations in muddle because they are damaged. This can include nerves that work for our motor system and nerves that work for our sensation systems. Sometimes they can cross over messages and that gets very confusing. As your bladder gets full it can trigger a spasm in

your legs. When it is emptied they can settle down. Sometimes a urine infection will do the same thing

**Kate:** Thanks for the 'hot inside' explanation, Vicki. I think that comes close to what I've been thinking about non MS pain triggering MS symptoms - so if I can get rid of the non MS stuff, then the MS symptoms will be less

**Linda - MS physiotherapist:** Hot or burning legs are a very common problem in MS. We health professionals call it neuropathic pain, although to you it probably isn't a pain but more of a strange sensation. It occurs because the nerves in the area of the brain and or spinal cord that deal with sensation have become damaged (either via myelin destruction or sometimes the nerve itself is damage). This means that the messages you receive from your skin, muscles, joints are not 'normal' and instead of touch you get a mixture of strange sensations. 300mg of gabapentin is a low dose, so you could discuss increasing this with your GP

**Vicki - MS nurse:** Spot on Kate. Sometimes another problem can act as a trigger or focus to provoke pain/discomfort messages from damaged nerves. Learning what the triggers are can help in managing better

**Kate:** Thanks Vicki. It has been very difficult getting the non MS stuff (not just my feet) diagnosed. Things are changing since I was referred to a community matron

**Linda - MS physiotherapist:** John, with your second question about spasmodic pain, it sound as though your bladder may be in spasm which is acting as a trigger to the leg spasm. By addressing the bladder problem it might be that the spasm overnight is then eliminated. There are also other options medication wise which might be better for overnight spasm.

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**Liz:** Is there any means of curing nerve pain without increasing the 'switched off' problem? All the medication I have been offered has been muscle-relaxing and/or sedating.

**Linda - MS physiotherapist:** Curing nerve pain is a difficult one. It is more about managing the symptoms if this is an ongoing symptom for you. You could try TENS, or some of the complementary therapies could take the edge off the symptoms if you are not keen on medication

**Simon - MS Trust:** Liz's question about the unwanted effects of drugs reflects a question from Julie earlier in the day about pain drugs that don't cause the side effects she experiences such as severe constipation and drying of the eyes

**Vicki - MS nurse:** It is important not to be afraid of using medication for pain and to talk to the doctor about the best therapeutic dose that works for you. Sometimes we use anti-depressants with very good effect for pain. It is also important to have a regular review of medication

**Ben:** Can I just add that I cope quite well with constipation brought on by pregabalin (Lyrica) by using glycerol suppositories from Boots.

**Vicki - MS nurse:** As Linda says, by using a range of non drug measures you can get a good response from lower doses of medication with less risk of side effects

**Liz:** Things like TENS, capsaicin cream, and all methods which require touching the body. These irritate the nerves and cause enormous problems - not just increased pain, but also increased disability.

**Linda - MS physiotherapist:** Sorry to hear about your lack of success, Liz. Have you tried relaxation or pain management strategies for trying to cope with the pain?

**Liz:** Yes, I have some success with visualisation and acupuncture. Relaxing increases the 'switched off' problem of course, so is only advisable if I don't want to do anything

**Vicki - MS nurse:** Have your medical team tried anti-depressants for this hypersensitivity?

**Liz:** Are there any anti-depressants which aren't sedating? I really need to be alert with my balance problem

**Vicki - MS nurse:** There are anti-depressants that are not sedating. Talk to your GP. If you decide to try them you will need to start low and wait for at least two or three weeks to see if they will work, so you will need to be patient. Not easy when you are in pain.

**Liz:** Thanks for the advice. I'll see my GP about anti-depressants

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**Mike:** Whilst my problem isn't so much pain as discomfort, it concerns being woken with very stiff legs during the night, which I believe is caused by some low level spasming/twitching. I sometimes get this during the day as well, but normally when seated for a while. I then have to get up and stretch to relieve the stiffness before I can get back to sleep, which is very frustrating, and adds even more to fatigue, which is a problem.

I'm currently taking gabapentin - 300mg morning, 300mg afternoon and 600mg before sleep - and clonazepam - 0.5mg afternoon, and 1.5mg before sleep. Getting to sleep is OK, but the efficacy of the drugs seems to be relatively short-lived (about five hours), and the stiffness of legs is getting quite a bit more of a problem recently (NB: bladder/bowel aren't a problem).

I have been in liaison with my neurologist, MS nurse and GP, which is where this regime has been developed over the last few months. Whilst I have total faith in them, do any of the experts have any further ideas to 'throw in the mix'?

By the way, I have been on Baclofen before, but the efficacy wore off, despite upping the dose, hence the gabapentin. I am relatively active - swimming, pilates etc - so not sedentary. I have had MS for 25 years, and am now secondary progressive.

**Vicki - MS nurse:** Are you using any pillows at night to make sure your knees are slightly bent and slightly apart? This can help. Do you have good mattress? You may also benefit from review of your medications

**Linda - MS physiotherapist:** It may be worth discussing with your neurologist the timing of your dose of clonazepam (eg taking it all before going to bed). Stretching prior to going to bed might also help and TENS has been helpful for

spasm and pain related to spasm overnight. It might also be worth looking at your sleeping position overnight as posture can affect spasm

**Mike:** I have tried pillows under my legs, and when lying on back this seems to be relatively effective (eg during an afternoon rest). But night-time is a problem as I sleep on my side, which makes it awkward to have pillows under the knees. As for my mattress, I have an excellent water-bed (no comments, please).

Since increasing the clonazepam, which I'd hoped would be more anti-spasmodic, I have also noted that my walking is somewhat weaker. I don't know whether that's a side-effect?

**Vicki - MS nurse:** It is difficult to know without seeing you what might be causing what. Are you on any disease modifying therapy? I won't comment on the waterbed!

**Linda - MS physiotherapist:** You could try sleeping with a pillow between your knees - it will help to keep your legs in a good position. There is also a t-roll you can use for positioning although this might be too bulky.

If you take all of your clonazepam at night, because it is relatively short acting it shouldn't have that much of an effect the next day. Obviously everyone is different and you would need to discuss this further with your team

**Mike:** Would that also have an effect on stiffness of limbs, as I have periods of spasticity during the day?

**Linda - MS physiotherapist:** It can help with muscle stiffness, although I think it's more effective for muscle spasm and pain. I have some patients that find it helpful but you would probably have to use it for two to four hours a day if you have constant stiffness. It's worth a try - at least there are no side effects!

**Mike:** Many thanks for your comments. I have got a neurologist's appointment in a couple of weeks, so will have the opportunity to progress things, hopefully!

**Linda - MS physiotherapist:** good luck, Mike

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**Isabelle:** I have MS and I am trying to live with it the best I can. I was diagnosed last November. I still manage a normal life but I have constant pains and aches and pins and needles.

The latest symptoms started a month ago and seemed to be exacerbated by my holiday in the south of France. I get strong pins and needles starting in my hands, and then funny feelings in my head, my bottom jaw feels strange and for about 10 to 20 seconds I cannot form my words properly. My speech gets a bit slurred. Then it passes and everything is fine. I got from one to up to ten of these 'turns' a day while on holiday, but now it maybe is once or twice a day, and sometimes nothing happens for a couple of days. Today also, it happened once and I was writing at the time and could not form my letters properly. It went after a few seconds.

Do you recognise these sort of symptoms? Have you heard this sort of symptoms before? How can I manage them? I am seeing my neurologist in a month and will speak to him

**Vicki - MS nurse:** Isabelle, did you spend a long time travelling? Prolonged pressure on certain points can trigger pins and needles. This can be prolonged for people with MS. It may be you have had a sensory flare up of your MS and it will slowly subside. You are not alone with these symptoms; it is sensory nerve problems. If they become very uncomfortable and distressing there is a range of treatments and strategies to help manage them.

**Linda - MS physiotherapist:** I would discuss these symptoms further with your neurologist or GP. Symptoms lasting for a very short time like you described are atypical of MS

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**Steven:** I have two main issues with pain. Firstly the knees. They are not stiff just very painful. I have problems with spasms in the legs and the MS nurse / GP differ in their opinion as to which causes which.

Secondly, I have been in shorts since April of 2006 because my legs are super hypersensitive to anything on them in the area of my knees

**Linda - MS physiotherapist:** Both problems you describe are very common in MS. Have you tried anything to help either symptom?

**Vicki - MS nurse:** Hello Steve. Is everyone confident that you don't have a mechanical problem with the knee joints? Were you a footballer at all? As we have mentioned earlier, another problem can trigger spasm but may need a different approach to resolve it

**Steven:** My medication is gabapentin 900mg three times a day, diclofenac 50mg three times a day, low dose tegretol (just started) and lots of Co-codamol. I have never been a footballer. I started golf after I was diagnosed in 1996. My knees have been x-rayed and nothing out of the ordinary found

**Linda - MS physiotherapist:** Does either gabapentin or diclofenac help with the pain or give you any side effects? The gabapentin could be increased to help with the sensitivity issue. Please discuss this with your neurologist/GP

**Vicki - MS nurse:** It is likely this is an MS problem and you say you can't bear trousers on your knees. Do you use a cradle to keep bedclothes off your legs at night? Tegretol is excellent and a slow release form is often better tolerated, so I hope that will work well.

**Steven:** Yes I need a cradle in bed. I will persevere with tegretol and hope for the best. Thanks

**Liz:** Hello Steven. My hypersensitivity is also greatest in the knees. Twenty years ago. I was in great trouble with the pain, and wore shorts a lot. Then I discovered tubigrips, and have worn them on my knees ever since. They allow me to wear trousers with much less irritation. I have to replace them fairly frequently and they're no good when they're washed

**Vicki - MS nurse:** some people have also reported that even the texture of their bedclothes can have an impact. Silk has the least friction and is also very thermostatically stable

**Steven:** Liz, I am sorry to hear you have this bloody awful problem as well. I tried tubigrip, but then my knees just feel as if they are 'locked in' and won't bend. It's not an issue in the summer (ha ha) but the winter gets me down.:-((

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**Jim:** I don't think my pain is the same as that described by Steven and Liz, but the tubigrip thing sounds similar to something I do. I feel a sort of tingly tightness in my hands which is not really painful but is a pain (if you see what I mean). I find if I wear a thin glove on my hand I can cope with the feeling. It's almost as I've given my brain a reason to have these sensations and so it can ignore them to some extent. Looks a bit weird perhaps, but it does seem to work for me

**Linda - MS physiotherapist:** TENS works in a very similar way to what Jim is describing with his gloves. The mechanism is the pain gate theory where if you input another sensation it closes the gate to pain so that it is the other sensation you are feeling rather than the pain. TENS also stimulates the release of endorphins which are your body's own painkillers

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**Laura:** For the past few months I have had constant pain, numbness, pins and needles in my hands. Anything I can do to get rid of this??

**Vicki - MS nurse:** Laura, check back through the chat for a range of possible solutions that will help your problem. They include TENS, anti-convulsant medication such as gabapentin, anti-depressants such as amitriptyline (even though you might not be depressed they work well), yoga and relaxation therapy. And rest!

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**Peter:** I suffer from quite severe nerve pain, particularly in my legs. I take 500mg of lamotrigine per day and Co-codamol when it is at its worst. The pain is at its worst when I am lying in bed. I am wondering why this should be, and what I might do to help reduce the pain at this time?

**Vicki - MS nurse:** We have talked about the importance of positioning at night; when you are stretched out flat the pains can be worse. The timing of your medication is also important. If they get really bad a small dose of diazepam can be really helpful too.

**Linda - MS physiotherapist:** Nerve pain is typically worse at night. This is partially because your body is relaxed and you are more aware of it than rather than during the day when you are thinking about other things. An anti-depressant like amitriptyline could be added at night to help with the pain. Also we have had some success using TENS (which is a portable electrical stimulator) for a minimum of an hour prior to going to bed.

**Peter:** Thanks very much for your suggestions.

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**Kathy:** I am 60 years of age and have had secondary progressive MS since diagnosis in 1997. In the last 18 months to two years I have suffered very painful muscle spasms every couple of months or so around my rib cage. There is also more numbness around my chest area when I have a spasm. I have found it quite frightening not being able to breath deeply because of the pain which can last several hours.

I have been prescribed baclofen (10mg) by my GP, who is wonderful, and he said to take one to two tablets twice a day when you feel a spasm coming on and it should take about two hours to work. I am so frightened to get these spasms that I have tried taking one tablet every day when I haven't a spasm to relax the muscles but have had to stop as it made my body, especially my legs, so weak. There is a note on the tablets saying "Don't stop taking this medication only on doctor's advice" Could this be explained please? I have deteriorated over the years but still try to keep mobile with my four wheel rollator. I could possibly cope with most spasms anywhere else but not in this region.

**Vicki - MS nurse:** Kathy - try taking half a tablet (5mg) at a time. Perhaps one in the morning and one in the afternoon if the spasm is happening everyday. You are probably having too much baclofen in one go.

**Linda - MS physiotherapist:** Sorry to here about your spasms around your ribs. How often do they happen and is there any triggers that you can think of that might be bringing the symptoms on?

As a side effect, baclofen can cause muscle weakness which can have a negative impact on walking, so it sounds as though it is not a particularly helpful drug for you. If you have been only taking one a day it is OK to stop taking them. The problem comes if you are on much higher doses (say four to six tablets daily) when you can develop serious side effects on abrupt withdrawal and it is always recommended to slowly alter the dose when increasing or reducing the dose.

Does the baclofen help when you get the spasms? If not it might be worth discussing other options with your GP. If the spasm are happening regularly and taking the baclofen is knocking off your walking, it might also be worth looking at other options. Gabapentin might be more effective and has less of the side effects you describe. Hope this helps

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**Brian:** Hello, wanting to ask a few questions about numbness and pain in the feet. I was just diagnosed in March so this is all too new to me.

**Vicki - MS nurse:** Hello Brian. It is very hard when it is still so new. Numbness and pain in the feet is not uncommon in MS and there are lots of things that can help. We can't 'cure' these problems but a range of things will alleviate the symptoms if they don't settle of their own accord.

If you look back through some of our chat you will find many suggestions but the key thing is to tailor things to meet your exact needs. Every person with MS is unique in their presentation and their problems. If you have an MS team to support you, speak to them.

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**Peter:** I had a major relapse back in December and although the pain is manageable now I was wondering if you could recommend anything for me to do or take to try and relieve the pain completely. I don't want to take anything that is illegal but I'm open to try anything that can help me. The pains are mainly in the shins and I can't walk too far without becoming breathless very quickly.

**Linda - MS physiotherapist:** It is not always possible to relieve pain completely, however there are a range of licensed medications available which could help. Neuropathic pain is often aggravated by activity although usually settles within 30 minutes post exercise. So it's not a reason not to exercise. The breathlessness is probably relating to your relapse and you may be out of condition. As your fitness improves you should find that you can walk further without being as breathless. Physiotherapy may help improve walking, fitness and stamina

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**John:** I am a 62 year old man who has had MS now for about six years. It started as transverse myelitis, quickly developed into relapsing/remitting MS but has now become progressive.

My second relapse, about five years ago, brought with it severe neuropathic pain to my right hand and wrist especially when the ambient temperature falls below 22 degrees C. It seems to translate the feeling of cold into pain. My therapy for this consists of 200mg pregabalin three times a day. During hot weather I can reduce this to 100mg three times a day. Wearing a fingerless glove also helps. The pregabalin significantly reduces the pain but whenever I touch something my fingertips and especially my wrist and palm still have very uncomfortable dysesthesia.

Is there any better therapy please that may not only dispel the dysesthesia but help to return my touch sensation towards normal?

**Linda - MS physiotherapist:** This is a difficult one. It sounds as though your pain is controlled well by pregabalin and you are on the maximum recommended dose - although you could discuss an increase beyond this with your neurologist. I'm not sure whether this would help with your hypersensitivity or whether any other medication would be more effective. Going back to previous suggestions re TENS, reflexology, wearing a glove, relaxation etc, they may be worth trying. In terms of the return of sensation there is no medication available which can offer this kind of help

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**Irene:** I have aggressive primary progressive MS and, as such, disease modifying drugs are off limits for me. Moreover, my age and other medical problems mean that I am not able to be included in drug trials.

I have the usual medicines - baclofen, gabapentin, amitriptyline and clonazepam. A consultant neurologist has suggested that I might wish to try Sativex to relieve pain and spasms.

What does the current research say about Sativex, and what anecdotal evidence is there for its efficacy in primary progressive MS? What other medicines might help relieve my pain and spasms?

**Linda - MS physiotherapist:** Tizanidine and dantrolene (not used very often now) are other options for spasticity. Pregabalin, lamotrigine and tegretol can be effective for neuropathic pain.

We have a number of patients using Sativex with variable response. Our unit has been involved in a variety of trials for cannabinoids for pain and spasticity in MS and I was at a meeting at the recent ECTRIMS conference where the preliminary results of a trial using an oral cannabinoid reported very positive results for muscle stiffness, pain, spasms and sleep quality. As has been previously discussed there is a lot of anecdotal evidence and Dr Lieberman's explanation earlier explains the action in a much better way than I could attempt

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**Adrienne:** I seem to be experiencing lower bowel pain each morning when I wake up. It is quite severe and seems to ease off when I sit up in the wheelchair. I have been wheelchair-bound for about seven years now and the only method I use to empty my bowels is by using a bisacodyl suppository every two days. On consulting my doctor regarding this pain, I had a stomach x-ray which revealed nothing untoward. Having spoken to the MS nurse both at home and at the MS therapy centre in Bedford, which I attended weekly basis, they seem at a loss to explain this. I eat well regulated diet and can think of no reason for this pain. Have you any ideas please?

**Linda - MS physiotherapist:** Sorry I'm not able to answer your question very well as I feel this is outwith my scope of practice as a physiotherapist. The MS nurses or continence nurse specialists would be better placed to help. I do remember visiting one patient who had a similar sounding problem to you which I think was not MS related and he was on medication for it. In general if you can remain as active as possible this will help regulate the bowel and I know that some of our patients get a great benefit from using an active passive trainer (its like a motorised static cycle). Reflexology may also be helpful

**Simon - MS Trust:** Adrienne, has anyone assessed the pain as potentially not being linked to your MS? Someone mentioned earlier that his GP had assumed MS was the cause of his pain but it turned out to be coincidental

**Adrienne:** I suppose that problem is not MS related, more to do with my being in a wheelchair 17 hours a day. Should I approach the occupational therapist or the MS nurse or the doctor regarding the passive trainer? I am 59 years old and do not take any medication for MS other than LDN, and Co-codomol for leg pain at night if it becomes unbearable. Perhaps the LDN and the Co-codomol could be causing the pain?

**Simon - MS Trust:** Have you seen our book on posture - *Are you sitting comfortably..?* (see the Resources section at the end of the transcript). This was written by a physiotherapist for people who spend much of their time sitting. The pain may be unrelated, but considering posture is important.

**Linda - MS physiotherapist:** Co-codamol can cause constipation which could be contributing to your bowel pain. You have to weigh up the pros of taking Co-codamol. Is it effective for your leg pain at night? If not, there might be another medication which would be more effective and less constipating. You can discuss this with your GP.

I have not heard of any side effects from LDN. Simon might be able to help with getting some info on this.

The physiotherapist would be the best person to approach re the active passive trainer although I cant guarantee that they will have one in your local physio department. A number of our patients have bought them to use at home with good effect (some with grants from the MS Society). Why don't you Google active passive trainer (APT) and see what comes up.

**Adrienne:** I have read the book on posture. I do yoga on a weekly basis and have been doing it to 27 years or more, so I'm aware of how to position my body. The MS physiotherapist at Bedford MS centre checks on my posture. Perhaps the passive exercise machine mentioned might help with my circumstances - my bowel problems I mean! I must admit that I seem to be the only one with MS that I know who has these problems. I'm just looking for any suggestions really.

**Simon - MS Trust:** We have a factsheet on LDN (see the Resources section at the end of the transcript), though I'm not aware of constipation being a side effect.

**Adrienne:** I understand from a doctor friend of mine that LDN can cause constipation but only when it is taken in high dosage, which is clearly not my case, I also believe that the Co-codmol can cause this too so I avoid taking this. My doctor seems perplexed at the pain which I have suffered for about seven years, so maybe linked to being in a wheelchair and being inactive.

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**Pat:** I was diagnosed with relapsing/remitting MS in June this year after 20 years of mainly sensory symptoms, two bouts of optic neuritis and a severe relapse involving my mobility last year which led to my diagnosis. One of my most debilitating symptoms is pain and today my specialist nurse suggested that I might be experiencing atypical trigeminal neuralgia. I know that has already been discussed today so my question is more around controlling pain enough to cope at work as I work full time too. No one can see the pain I have and therefore it is difficult to handle in the workplace - any suggestions welcome please?

**Simon - MS Trust:** Did the nurse suggest anything today?

**Pat:** I am taking gabapentin at the moment and slowly building the dose. She mentioned other drugs that might also help. So I am aware of the need to find the right medication to control it. It is more about the handling of others who can not see the pain you suffer and that it might look as though you are trying 'duck' work lol

**Linda - MS physiotherapist:** It might be worth leaving some of the MS Trust and MS Society information leaflets on pain for you work colleagues to read at their leisure. This might help with their understanding of your symptoms. What are you currently taking to control the pain?

**Pat:** Good idea about the leaflets - the working with MS worked with my manager at least so worth a try. I am taking gabapentin

**Simon - MS Trust:** The MS Trust has a factsheet on pain. The MS Society has something on pain and sensory symptoms (see the Resources section at the end of the transcript)

**Linda - MS physiotherapist:** Your MS nurse would also come out and speak to your work colleagues and manager if they were interested. It's really important to have their support and understanding. It will make it so much easier for you to pace your workload to help manage your MS symptoms

**Pat:** Thanks - yes I have read the leaflets and must return to them as it was quite soon after my diagnosis and you don't always take it in at the time. How do I know that it is trigeminal neuralgia as it doesn't seem as severe as the descriptions I have seen?

**Linda - MS physiotherapist:** Can you describe your symptoms?

**Pat:** I get a boring / burning pain which starts either in or above or in front of my ear and spreads to parts of my face usually down the jaw but sometimes to my eyelid

**Linda - MS physiotherapist:** It certainly sounds like trigeminal neuralgia. People experience different severity of pain.

**Pat:** Thanks Linda and Simon I will try the tips for work and keep on trying the medications as this is all new to me. Great chatroom today - thank you all for your time

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**Liz:** Hi. Any pain relief to help with the constant head pain I've had for five years after a relapse of optic neuritis? Other pains from MS are joint pain in hands and legs. I have tried lots of anti-depressants and different combinations. Nothing is helping. I'm due to go into National Hospital for treatment for chronic migraine. I'm not sure whether it is MS or migraine, although I never suffered with migraine before

**Linda - MS physiotherapist:** It sounds as though you are going to the right place as it may well be migraine. A recent study showed that headache was no more frequent in people with MS than in the non-MS population. Joint pain again is not directly related to MS and may be better assessed by a physiotherapist and treated with an anti-inflammatory

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**Annette:** I wonder if you can help? I have terrible pain down my right arm through to my finger tips. It's like a burning sensation, with numbness and tingling and it's coupled with a feeling as if needles are being pushed down to my fingertips. I'm on gabapentin but it seems to have no effect, as I wake up every night with the pain and have done so for a year now. Can you help please?

**Linda - MS physiotherapist:** It may be that you are not on an effective dose of gabapentin or need to try another medication for pain. It does sound like nerve pain although sometimes pain travelling down one arm like you describe could be coming from your neck - worth bearing in mind and discussing with your GP/neurologist. If this is the case referral to physiotherapist might be helpful.

**Simon - MS Trust:** Annette, Ilan had good advice on the basic approach to pain management at the start of today's chatroom. Ideally you could ask to be referred to a pain clinic, but there are some basic steps that could be taken to look for an effective treatment. It is an area where it takes a while to find what is suitable for the individual

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**Simon - MS Trust:** We've got to 7 o'clock and it's time to draw today's chatroom to a close. Thank you to Linda and to Ilan, Kate, David and Vicki earlier in the day. And thank you to all the people who asked questions and made comments

## **Resources mentioned in the chatroom**

Other than our own publications, the MS Trust can not vouch for the content of the information listed

### **MS Trust**

#### **Books**

- Are you sitting comfortably..? (posture when sitting)
- At work with MS
- Disease modifying drug therapy
- Exercises for people with MS
- Living with fatigue
- MS explained

#### **DVD**

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

#### **Factsheets**

- Cannabis
- LDN (low dose naltrexone)
- Pain
- Sativex
- Spasticity and spasms

#### **Website resources**

- Map of MS services - [www.mstrust.org.uk/information/services/](http://www.mstrust.org.uk/information/services/)

#### **StayingSmart** - [www.stayingsmart.org.uk](http://www.stayingsmart.org.uk)

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

#### **Open Door articles**

- Hippotherapy - a new movement experience - May 2006 pp 10-11

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

All of these publications are free apart from the DVD

### **Contact the MS Trust to order publications or to join the Open Door mailing list**

MS Trust, Spirella Building, Bridge Road, Letchworth Garden City, SG6 4ET  
01462 476700  
[info@mstrust.org.uk](mailto:info@mstrust.org.uk)

Contact the MS Trust Information Service  
01462 476700  
[infoteam@mstrust.org.uk](mailto:infoteam@mstrust.org.uk)

## Other resources mentioned

- National Institute for Health and Clinical Excellence.  
Draft guidance on Pharmacological Management of Neuropathic Pain in Non Specialist Settings  
NICE; October 2009.  
see the NICE website at <http://tinyurl.com/nice-pain>
- MS decisions - [www.msdecisions.org.uk](http://www.msdecisions.org.uk)  
a website for people considering their options with the disease modifying drugs
- MS Society. MS Essentials 17: Pain and sensory symptoms  
0808 800 8000 / [www.mssociety.org.uk](http://www.mssociety.org.uk)
- Pain Concern  
0844 499 4676 / [info@painconcern.org.uk](mailto:info@painconcern.org.uk) / [www.painconcern.org.uk](http://www.painconcern.org.uk)  
a charity providing information and support for people affected by pain
- Schneider M, et al.  
The handbook of self-healing: your personal program for better health and increased vitality  
London: Penguin Books; 1994.