

MS Society Expert Web Chat
21/04/2004 2-3.30pm (UK Time)

Pain & MS
With Dr Barbara Chandler



laila (moderator)

Welcome Dr Chandler to today's guest chat. The topic is Pain & MS.

For information - the next chat will be in June, look out for more info on site soon.

Dr Chandler is a Consultant in Rehabilitation Medicine based at the Specialist Neurological Rehabilitation Services Division in Newcastle Upon Tyne.

Questions from email

1. My legs get so cold they hurt; this is a symptom I have experienced since having MS. I use a wheelchair full-time but this was a problem when I was still able to walk so I guess it's not just down to circulation problems due to lack of mobility. Can you please give a neurological explanation? 2. Also my lower back area (lumbar area) either side of my spine is extremely painful when touched. Is there a possible neurological explanation? Thank you - Venice Edgar

Dr Barbara Chandler (Guest Speaker)

Thank you for your question. The cold feeling you describe may well be caused by the nerves. Although your legs may well get cold now that you use a chair, as you have had this feeling for so long I think it is a "false message" from the nerves. This is a form of neuropathic pain. This is a common type of pain in MS and does not respond to the ordinary painkillers. You could discuss this feeling with either your doctor or MS nurse and there will be some medication you could try.

Questions from email

Hello, I have got RRMS, and suffer with chronic pain on my right hand side, from the back of my head to the bottom of my foot. It is a burning pain, and is extremely uncomfortable. I have tried numerous medications, and they don't seem to be helping. I'm about to start another course of physiotherapy, and just wanted to know if this is going to be the path of the course of my MS. - Di Smithson

Dr Barbara Chandler (Guest Speaker)

Di, thank you for your question.

You are clearly having a lot of problems with severe pain. You have had very little success with treatment by the sound of it. I would suggest that you seek a specialist opinion from a pain clinic. Your GP or neurologist can refer you. It may be that you would be helped by a Pain Management programme that takes a much broader approach to dealing with pain. Also talk to your physio about alternative treatments such as acupuncture.

I hope this helps.

Questions from email

I have MS and I'm experiencing severe pain in my feet. What can I do to ease the pain? - Anna Di Genova

Dr Barbara Chandler (Guest Speaker)

Thank you Anna, It would be helpful to know more about the nature of your pain as different types of pain respond to different treatments. There are a variety of drugs to help with pain, but we need to decide if the pain is coming from the joints and muscles or from the nerves as they require different drugs. Also pain can result from being in one position a lot of the time or from your legs being "down" all the time. It may also be helpful to talk to a physio about seating and posture.

Questions from email

I would like to know Dr Chandler's opinion on how to deal with the pain I suffer after spasms. My legs shoot from flexion to extension with enough force to pull me from a chair and I often have to wait 20 minutes before I can recover my position. I have tried Diazepam & Ibuprofen, both don't help. I take Tizanidine, Baclofen & Nabilone as spasticity treatment. I am having physio and considering a Baclofen Pump. I also suffer extreme burning pain in my feet (heels mostly) and my reaction to this additional pain triggers spasm. I thought maybe Gabapentin but my GP has referred me to a vascular surgeon(?). Any suggestions? - Gina Griffith

Dr Barbara Chandler (Guest Speaker)

Thank you Gina. Your spasms sound very troublesome indeed. Gabapentin is a particularly useful drug in this situation as it works for both nerve pain (the burning feeling you have) and for spasms. I don't know what dose you are taking, but with your doctor's supervision and depending on side effects Gabapentin can be slowly increased up to quite high doses which may then become more effective than your current dose. I see you are also considering a Baclofen pump, this can be extremely good at controlling spasms and the pain related to spasm. Have you talked to other people who have had a pump?

Questions from email

Dear Dr. Chandler, I get severe crushing pain in the whole of my left arm accompanied by visual disturbance. The pain usually occurs during the night and

lasts for up to 3 hours. I have been taking two 50mg tablets of amitriptyline at night for the last 10 years. I recently tried quinine tablets, which controlled the pain for about six months, but they are no longer effective. I would appreciate your advice, Many Thanks - wendy le croissette

Dr Barbara Chandler (Guest Speaker)

Thank you for your question. Am I right in thinking you have had the same type of left arm pain for the last 10 years? One thing to try and work out with your doctor is whether this is MS pain or pain from a different cause or a mixture of both. Different pains require different approaches. Often to achieve good pain control a combination of treatments is required, so you may benefit from an additional medication. Also a review with a physio would be helpful as pain can result from the way you sit or in particular the way you lie in bed. Have you had a recent review of your pain with your doctor?

Questions from email

I'm 56 and have SPMS. I have suffered from severe pins and needles in arms, legs and perineum for about 8 years. I have had spinal morphine injection, Neurontin and now Lamotrigine. This final medication has reduced quite a bit of the arm and leg pain, but not the perineum. This makes it uncomfortable to sit/drive a car. Any suggestions please. - Peter Caldwell

Dr Barbara Chandler (Guest Speaker)

Thank you Peter. Your pain has been difficult to bring under control by the sound of it. It is good to hear you have had some response to the recent drugs. As drugs have generally been of limited benefit I would suggest also looking at non drug management such as acupuncture and TENS. These can be effective and it may be possible to use them for the perineal pain. Also ensuring that you are comfortably seated is very important so there is as little additional discomfort as possible. A specialist physio or Occupational Therapist could advise on seating.

sam

I saw something about Jerry Lewis using an electronic device imbedded for pain - could this help with the types of pain you get with MS?

Dr Barbara Chandler (Guest Speaker)

Thank you. It is possible to stimulate the spine with an implanted device and this is done in very specialist units. It is not the best or appropriate treatment for many people with pain. More information could be obtained from your neurologist or pain specialist.

Questions from email

I have the symptom called banding (tight band feeling around waist). It has never gone away since a relapse about 2 - 3 years ago. Is there anything to help relieve this? Many thanks - Marina Griffiths

Dr Barbara Chandler (Guest Speaker)

Thank you Marina. This is a common type of feeling / pain in MS and is distressing. It can respond very well to medication. It does not respond to the usual painkillers like Paracetamol. It does respond to the special drugs used for nerve pain these are drugs that are often more commonly used for other conditions such as depression or epilepsy. You should talk to your doctor or MS nurse and they can suggest one of these medications for you to try.

Questions from email

I've just been through my 4th relapse which initially affected my bottom half but, now these problems are fading a little, I'm experiencing a severe pain around my middle, as if wearing a very very tight belt, restricting my breathing and feeling very sore. My GP is not sure that this is caused by MS but cannot find any other cause. My question is, has anyone else had this problem and is it MS? - Janis Cox

Dr Barbara Chandler (Guest Speaker)

Thank you Janis. Band like sensations are very common in MS and are an unpleasant type of MS pain. It is likely to be the MS causing this. It may well be helped by the drugs for nerve pain. These are drugs most commonly used to treat depression or epilepsy but they have been found to be effective in nerve pain. Speak to your GP about this. Also you and your GP might find helpful information from an MS specialist nurse or your neurologist.

Questions from email

My brother has MS, possibly for the last 12 years, 1st attack at 18. Over the last 2-3 years he has had no major attack however he is now experiencing constant numbness and a tingling sensation in his hands and feet which he never had before, he has become unsteady and is suffering a lot of pain and stiffness in his legs. Please can you let me know if this is secondary progression? Will any medication such as interferon or copaxane help his condition? Your response is greatly appreciated. Thanks - Yasmin Hassan

Dr Barbara Chandler (Guest Speaker)

Thank you Yasmin. It is very difficult to say exactly how your brother's condition is progressing without seeing him. As he has developed new symptoms I would certainly recommend that he has a review with his neurologist or rehabilitation consultant. The type of tingling you describe is common in MS and if it is causing problems could be treated with medication. It sounds as if it is really important for your brother to be reassessed and then advice about treatment can be given.

Questions from email

What progress has been made in the use of cannabis and its availability and its use for MS pain - Anna

Dr Barbara Chandler (Guest Speaker)

Thank you Anna. There have been a number of studies published about the use of cannabis for pain and spasm. The results show that some people do find the use of cannabis based drugs very helpful and anecdotally we know this is the case. Trials of drugs are ongoing and drug companies are aiming to obtain a licence for a treatment. At the moment we are just waiting for more results and the licensing of a drug. As with many treatments it is likely that such drugs will work will for some people but not for others.

laila (moderator)

More information on cannabis research is available in our research faqs:

http://www.mssociety.org.uk/research/research_explained/faqs.html

Questions from email

After 10 years of resting during relapses (in particular the area being 'attacked'), I am controlling pain by gentle stretching exercises of my hand and arm. This eases excruciating pain between my thumb and forefinger in particular. Therefore should physiotherapy be used during an attack? - Iris Coleman

Dr Barbara Chandler (Guest Speaker)

Thank you Iris. Yes physiotherapy has a very important part to play in management both in terms of exercise and maintaining good posture. There is now a lot of evidence to support the use of appropriate exercise both active and passive. During an attack if you are very fatigued you may be limited in how much you can do but some stretches and a limited regime will avoid for example joints stiffening up too much. It is always helpful to have advice from a specialist physio who has experience in advising people with MS. The physio can help you find the right balance between exercise and rest.

Questions from email

How can / should practitioners assess whether pain is of neurogenic origin or pain from muscle in spasm? Thanks - Karen Angus

Dr Barbara Chandler (Guest Speaker)

Thank you Karen. Sometimes it is very difficult to decide the exact origin of pain however there are certain indicators. Pain that is difficult to describe and may be tingling, burning, creeping or band like is often nerve pain. Pain that is more of an ache or definitely related to movement or spasm may be muscular. However some nerve pains are triggered by movement – so it is not easy. Part of discerning the type of pain may come from seeing the response to treatment. Treatment itself may be physical eg stretches or drug based treatment. It is often helpful to discuss symptoms with a colleague who is more experienced if it is particularly difficult to decide on the best course of action.

smartie

I get a lot of lower back pain, which I would describe as a constant ache at best. I don't get muscle spasm in my back but can sometimes feel the muscles are very tight. Any help or advice

Dr Barbara Chandler (Guest Speaker)

Thank you. Back pain is very common and is not necessarily due to MS. It may respond well to physiotherapy through looking at posture and exercise. Other physical treatments such as acupuncture or TENS may be successfully used. I would certainly suggest a physiotherapy review.

Questions from email

Hello Dr Chandler, I'm 21 and on avonex. I get terrible aching/ burning/ stabbing pain in my thighs when I try to exercise, this usually starts to happen within 30 seconds of exerting even light exercise and it makes it almost impossible to take part in any cardiovascular activities. Would this class as interfering with everyday life and if so is there any medication that my GP/neurologist would be willing to prescribe so that I can start to exercise once again? - Thank you so much for your time. - kim

Dr Barbara Chandler (Guest Speaker)

Thank you Kim. There may well be medication that would help with this problem. However I would suggest having a review with a physio in the first instance to try and decide where the pain is coming from - whether it is a nerve pain predominantly or whether it is musculoskeletal pain. If the type of pain can be characterised this will guide your doctor in the type of medication they will choose for you.

Questions from email

I have many pain symptoms, which on first examination look like i have a bad-back, including sharp pain on bending, which is relieved by lying on my front. Crushing -type back pain which comes on at the end of every four hour period when my pain killers-Gabapentin, 2,400mg daily,& Tramadol 400mg. in addition i have both sharp and aching types of pain in my legs at some point every day. in fact for me pain is the worst aspect of my ms. I am able to walk a short distance but it is usually pain before fatigue that prevents me going further. I have'nt found many people yet who say this is the most debilitating aspect of their condition. do you have any figures about this? or any contacts i could access? - Miriam Morgan

Dr Barbara Chandler (Guest Speaker)

Thank you Miriam. Studies have found that up to 30% of people feel that pain is their worst symptom. For some people pain really takes over their lives. It sounds as if you are having a really bad time with pain. Often pain in MS will not respond to one drug only and I see you are on two different types of drug. It would be possible to increase the dose of Gabapentin further if your doctor felt this was advisable. There are a number of drugs that can be tried or added in and also

physical treatments such as TENS and acupuncture. Often there is more than one type of pain in severe pain and one may respond well to one treatment whilst not responding to another. You may find if your pain is not being well controlled your doctor may suggest you go to a specialist pain clinic where you can have an expert assessment of your pain and try some specialist treatments. Joining a pain management programme can also help some people as it helps **you** take control of your symptoms. You would find out more about this at a pain clinic.

Questions from email

On the news w/c 5/4/04 there was an item on an operation to insert pins close to the spine, which seemed to help. Is this operation widely available? - Peter Caldwell

Dr Barbara Chandler (Guest Speaker)

Thank you Peter. I am not sure exactly what this operation was. I am afraid I did not see the news item. However I will try and make some enquiries.

laila (moderator)

Peter - I will pass your email onto Dr Chandler

Questions from email

As a newly diagnosed patient I want to know what alternative therapies are available to me for chronic back pain besides a lifetime sentence of painkillers, which seems to be the only option for me. - Melanie Woodfield

Dr Barbara Chandler (Guest Speaker)

Thank you Melanie. You are certainly not alone in not wanting to spend all your time taking painkillers. There are now well-established pain management programmes that take a different approach to pain aiming to enable people to manage their pain through a variety of techniques. Sometimes this will be used alongside conventional and / or complimentary therapies. Pain management programmes are generally run through specialist pain clinics. Other treatments that are routinely offered through neuro-rehabilitation include acupuncture, physio, TENS, and management of related symptoms such as fatigue

Questions from email

I suffer from RRMS, and have severe chronic pain. I have taken untold medications for this symptom; it takes the edge off for a few days, and then flares up really badly. It is a very depressing symptom. Is there any connection with MS and arthritis? - Diane Smithson

Dr Barbara Chandler (Guest Speaker)

Thank you Diane. Arthritis is a very common problem in the population. It is therefore not uncommon for people with MS also to have joint problems and these can be particularly troublesome if you have additional muscle problems from the MS. Pain from arthritis responds well to certain treatments such as anti

inflammatory drugs and physical measures such as heat, TENS acupuncture.
Talk to your physio and GP about this

Questions from email

I have trigeminal neuralgia, which is treated with tegretol. However, I also have a stabbing pain going up the left side of my neck. This pain is brought on only when I laugh, or by chewing/yawning. It is very debilitating and causes flickering in my face. It causes my heartbeat in my neck to go crazy until the pain subsides after a few minutes - any idea what this could be? Thank you. - Deanna

Dr Barbara Chandler (Guest Speaker)

Thank you Deanna. The pain in your neck sounds very like your trigeminal neuralgia and this is called a "paroxysmal" symptom. It is probably best controlled by the same type of drugs that treat your neuralgia. It may be you need to increase your dose of Tegretol if your doctor thinks this is appropriate. Alternatively an additional drug for nerve pain may be needed. Talk to your neurologist about the pain.

Questions from email

Why am I getting burning pains in my legs (mainly right) and what can I do for it. I take Co-proxamol for pain, which dulls it down, but nothing is helping with burning. - Isabel Pringle

Dr Barbara Chandler (Guest Speaker)

Burning pains sound like nerve induced pain and this is common in MS. This type of pain does not respond very well to ordinary painkillers so it is quite common for people to find that these painkillers do not help very much. Nerve pain responds to particular drugs that are often used to treat other conditions - depression or epilepsy. These drugs can be very successful in stopping or reducing this type of pain. Explain to your doctor that you are having this burning feeling and your doctor will try you on an appropriate drug.

laila (moderator)

I'd like to thank Dr Chandler on behalf of all visitors to the room

laila (moderator)

We can't accept any more questions now but a transcript will appear on the website in the next few days

Thanks Dr Chandler.