



Spasticity and spasms

Chatroom

23 November 2010

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23 November 2010 - 10am to 7pm

- **Jon Marsden** - Professor of Neuro-rehabilitation
- **Jenny Freeman** - Reader in Physiotherapy and Rehabilitation
- **Val Stevenson** - Consultant Neurologist
- **Heidi Cleary** - Neuro-specialist Physiotherapist
- **Lisa Buckley** - Spasticity Specialist Nurse

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

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MS Trust Information Service on
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Simon - MS Trust: Welcome to today's chatroom on spasticity, spasms and muscle stiffness.

Emma: I have noticed that as the weather is getting colder I seem to be suffering with achy joints and stiffness. My GP gave me pregabalin and gabapentin to help ease the stiffness and the pain but unfortunately neither agrees with me. Is there anything else I could take?

Tracey: My legs are stiff and painful at the best of times. The colder its getting the worse they feel.

Jon & Jenny: This specific question relates to medication and so we would suggest that Val Stevenson is the best person to give you advice on this. Val is coming to the chat room at 1 pm this afternoon.

Many people do report that the cold makes their joints and limbs feel stiffer. We have talked to some people who have found benefit from wearing warm clothing around the stiff joints (such as leg warmers, gloves or neoprene garments) although there is no scientific evidence to support this.

Sandra: I can relate to many of these right leg issues. I am in South Australia and the winter was cold (for us). When coldest I thought was exacerbating but it was the temperature. I get a weak right leg in summer but not the spasms. I find if I gently stretch the calf and hamstring muscle for five minutes that frees up the stiffness.

Emma: I am due to see my nurses tomorrow is there anything I could ask them for?

Jon & Jenny: Specific questions. It may be good to write down your side effects and symptoms and think about things such as what triggers your stiffness; how has it progressed over time or how it fluctuates during the day or with different activities. Think about when the side effects started and when do they come on after taking the medication. They will also need to know whether you have you tried other drugs in past for these symptoms?

Lisa Buckley, who is a clinical specialist nurse and is on later, may also be able to give you some ideas.

Hellms: My walking is very restricted and my legs are very heavy feeling. I do as much as I can to stay active but it's hard.

Jon & Jenny: You are doing the right thing by trying to keep active. There is lots of extremely useful advice on different ways of keeping active both at the MS Trust website (Exercises for people with MS, Staying Active) and MS Society website (Exercise and physiotherapy).

Linda: For some years now I have the usual symptom of my leg stiffening and pulling tight when I lie down. It's as if someone is holding it bolt straight and stiff and it can even hurt the muscles at times. Hence, I turn on my side and pull my leg up towards my waist which relieves this. It also affects my swimming in the same way. My question is: if I resort to baclofen or whatever is on the market right now will it have the side affect of making me tired or even give me weaker legs when I attempt to stand up?

Jon & Jenny: What you are doing to immediately relieve the spasms seems to be working well for you, which is good. It would however be worthwhile making an appointment with a physiotherapist who can assess you and give you a programme of stretches, exercises and advice about the best way to manage these spasms. For example, the therapist will talk through with you issues such as your sleeping position and possible other triggering factors. It would also be worthwhile talking through this with your neurologist or MS nurse as it may well be that medication could be helpful for you without significantly impacting on your weakness.

Linda: I swim twice a week and am a fairly strong swimmer. My right leg is OK doing the crawl but not the breast stroke where it has to bend. I am fine all day. It is only at night or any time I lay flat that I have this problem with my right leg shooting out and staying rigid. I feel seeing a physio isn't the answer since I was given exercises a few years ago. That is why I wondered about taking some medication or Sativex at night that might help.

Jon & Jenny: You are right that medication may be helpful and that is why it is worthwhile seeing your GP, neurologist or MS nurse about this.

However, things change over a couple of years and so it would be worthwhile being re-assessed by your physio to see if any specific stretches or positions could help you.

Jayne: My leg spasms are worse at night, but clonazepam just before I go to bed really seems to help.

Claire: I take tizanidine and do my physio to control my stiffness. In the longer term, are any new drugs or treatments being developed to further manage or banish stiffness?

Val - neurologist: There are a few drugs out there to help with stiffness and pains. The main ones are baclofen, tizanidine, gabapentin, clonazepam or diazepam, dantrolene and Sativex. If it's spasticity, baclofen is a good place to start. There are no serious side effects and you don't need blood tests to monitor it. There are a few trials about to start on other anti-spasticity agents but none about to appear on the market that I know of.

Bigbird: Val, you say there are no serious side effects with baclofen. I found that I had increasing urinary frequency, especially at night, which of course caused lack of sleep, which causes endless other problems. I call this a serious side effect.

Val - neurologist: By serious side effects I mean liver failure or problems that don't resolve immediately after stopping the drug. I agree urinary frequency is a

serious problem and not usually caused by baclofen. There is often an underlying infection if it suddenly comes on or gets worse. It's worth taking a sample to your GP.

Bigbird: The nurse had to agree that the increased frequency was caused by the baclofen as she'd had other patients complain of the same side effects. Once I stopped baclofen the frequency stopped.

Chris: What are the possible baclofen side effects?

Val - neurologist: The most commonly reported side effect of baclofen is floppiness or weakness in the legs. This is usually a sign that it is working and the dose is just too high or in fact all the tone is needed to maintain function.

Like all drugs reducing the spasticity is the easy bit, maintaining or improving function is more difficult.

Other side effects are drowsiness or cognitive blunting - lots of people report their thinking skills are just not as clear when on these drugs as when off them. It can also cause dizziness, nausea and stomach upsets- it can cause gastric ulceration.

Having said all that, at low doses it can be a very useful well tolerated drug. I still use it as my first line drug as it is effective and doesn't need regular blood tests like tizanidine or dantrolene.

Tina: At night my lower legs get uncomfortable and only shaking them seems to help. It becomes almost like a nervous twitch. Not sure what I can do.

Christy: I suffer from what I call twitchy legs - a sort of involuntary jerk of one leg out from the knee like a kick. This is particularly at night and often when my legs are hot. It only affects one leg at a time and often switches legs after a couple of hours. I've tried basil essential oil mixed with lavender and that helps sometimes when massaged into the affected leg. When it's bad it keeps me and my husband awake. Is there anything else I can try?

Simon - MS Trust: Had you tried massage without the basil oil? Is the combination better?

Christy: Massage alone doesn't help it's definitely the basil oil that helps.

Wendy: I also have tremors or twitches when trying to sleep. Any advice?

Jon & Jenny: There are a few reasons why you may be feeling shakiness or twitchiness. For example, it could be spasms or spasticity or it could be restless legs. In the first instance you need to talk through this with your neurologist or MS nurse as it may well be that medication could be helpful. Physiotherapy can some times be helpful so it would be good to discuss with the neurologist or nurse whether a referral would be useful for you.

Geoff: What have people found most useful for their spasticity - either drug or not drug?

Jon & Jenny: Drug or not drug - this is very dependent on the individual, such as whether they get side effects, the dosage they need to manage their spasticity and their underlying level of strength. It needs careful assessment and monitoring by your team in discussion with you.

Neil: We are the Greater Manchester Neurorehabilitation Service. We are currently undertaking an audit aiming to measure the quality of service that people living with spasticity receive across the region. The MS Trust has kindly allowed us to use this forum to raise awareness that this project is ongoing.

We are trying to identify and approach service users and/or their carers to ask them about their experience of service provision helping them deal with their spasticity with the area of Greater Manchester.

We have developed a questionnaire in conjunction with the professionals who provide the service and have so far obtained feedback from 86 people but we would like to increase that number.

If you live in the Greater Manchester area and you experience spasticity or if you care for somebody who experiences spasticity and you would like to receive a copy of the questionnaire please contact Neil Connor on 0161 206 0538 or email me at neil.connor@srft.nhs.uk. Your help is very much appreciated.

Marlene: I would like to try Sativex but at the moment can only obtain it by paying for it. Does anyone have experience of Sativex and how does it help their spasticity and walking problems?

Eliza: I have been on Sativex for three months and I find it very helpful. I suffered stiffness for five years (and no one took me seriously) and neuropathic pain for longer. I now feel that some days I am 'normal' again. Is it OK to take Sativex with LDN? Or am I wasting my money on the LDN now? I have been on LDN for two and half years and have been free of relapses for two years. I dare not not take it. However could one work against the other? And is there anything else that works on neuropathic pain and stiffness?

Marlene: Are you able to obtain your Sativex through the NHS?

Eliza: Yes, I found out about it at a pain clinic and sent to a rehab neurologist, so it is supplied by the NHS. My LDN is private. It is the best thing I have had in the last 11 years. I do fear it will be taken away by the NHS. Also I do fear long term usage. I use it as little as possible.

Geoff: I have friends who have tried LDN and seen nothing. Others who swear by it.

Chris: What is LDN?

Simon - MS Trust: LDN is low dose naltrexone. The MS Trust has a factsheet on this.

Christy: Re LDN and spasticity, I've been on LDN 4.5mg for three years and am wondering whether I should go down to 3mg, but wary of losing the good effects like improved energy bladder urgency frequency. Also I only get the leg spasms sometimes so may stick on it.

Eliza: The LDN gives me energy and clearer thinking. The Sativex allows me to do housework, aqua aerobics and walk and other exercise without experiencing stiffness and spasms afterwards. I try not to take it easily, but it is helping me to keep moving. My hips are much better. Also it's the best thing I have had for neuropathic pain. Is it totally safe to use LDN and Sativex?

Val - neurologist: LDN is a tricky one; there is no evidence to say it works at all in MS. I can't see why pharmacologically you can't take them together though as they work on different receptors. High doses of naltrexone do need liver monitoring though.

Angie: I have a muscle which spasms in my right buttock making it very painful to sit at work. Is this caused by my MS or should I go see my doctor?

Jon & Jenny: We would certainly suggest going to your GP about this. Pain in the buttock could be caused by back and hip problems for example, rather than your MS.

Angie: Thanks very much, your advice is much appreciated.

Jim: I think my hip and back problems did come from my MS, or so my physio says. My stiff legs made my walking twisted and this has led to pain in my back.

Jon & Jenny: You raise a good point here Jim. Sometimes MS can cause your posture to be affected which in turn can cause low back pain. Sometimes however, just like everyone else, you might be getting back pain independent of your MS. Regardless of what the cause is there may well be treatments to help with this buttock / back pain.

David: Stiffness is problem for me. I have tried baclofen and botox and am now trying tizanidine and physio. Would love to try Sativex. Are we any closer to getting on NHS?

Redclift: My PCT says that they would consider Sativex but the first prescription must be given and monitored by my MS specialist. My MS specialist says that she can't prescribe. My PCT is East and Central Cheshire, the MS specialist is in Staffordshire. What is the best route to solve the dilemma?

Simon - MS Trust: Is it a specialist nurse or a specialist neurologist that says they can't prescribe?

Marlene: I have the same problems as Redclift with regard to being prescribed Sativex. My GP would prescribe it but has to go through the MS specialist in Canterbury who is saying that "until it has been decided who is paying for it" he will not prescribe it.

Jon & Jenny: The prescription of Sativex does vary throughout the country and it would be interesting to hear people's experience of this in this chatroom.

Bigbird: I live in Cheshire West and am having the same issues with Sativex. Walton Hospital won't allow the consultant to prescribe and the PCT won't allow the GP to prescribe. I take pregabalin but that doesn't seem much help. I have tried LDN but my GP won't now prescribe as he says consultant hasn't requested it and the consultant says he has.

I find cannabis a real help which implies that Sativex would help. I have a friend who takes tizanidine but finds it makes him stiffer than ever.

Alastair: I've been using Sativex for three months now - my GP prescribed it. I started off on one application a day and now I am taking four. Does it work? I think it helps. I am just about to start on LDN and have been reading that the 4.5mg dosage can be a bit too much for spasticity, the 3mg being more friendly. Has anyone any experience?

Val - neurologist: Sativex! It's one of the most common questions I get in clinic. It is now licensed but that doesn't mean your PCT will fund it.

The licence states it should be started by a MS specialist but hospital doctors cannot prescribe it until it is on the 'trust formulary'. I have submitted an application to UCLH in London but won't know until December 14th as to whether I've been successful. However I have worked with one GP who is happy to prescribe if I monitor, so it's worth asking your GP if they will help in this way.

Sativex won't help everyone. In the trials about half of people responded, so it's useful to try it for four weeks with assessments by your doctor or physio pre and post to assess whether it has helped. That way you can stop after four weeks if no change is seen.

To be honest if you've tried all the drugs available and you're now on to Sativex it is probably worth considering whether intrathecal baclofen (a pump) would be right for you.

Cynthia: I have secondary progressive and at the moment my legs feel like lead. I saw my neurology nurse last Friday and she has increased my baclofen, going from 10mg twice daily to 20mg twice daily. I have tried several different treatments including Zomorph, pregabalin, gabapentin, duloxetine, doselupin, amitriptyline, nortriptyline and none of these helped with the pains in my legs. Are there any other drug available?

Jon & Jenny: As you only started on the new baclofen dose last Friday, it would be worthwhile giving it a bit more time to assess its effectiveness. I would give it at least a week as symptoms can tend to vary a lot over a one week period. Val and Lisa may be able to discuss other potential avenues given that you have already tried a variety of medications.

Val - neurologist: Legs feeling like lead is a common description but it's really important to work out whether they are weak, heavy legs or spasmy stiff legs. The first will be made much worse by increasing baclofen, the second may be helped. It would be worth getting a physiotherapist assessment to work out the contribution of weakness compared to spasticity.

Sometimes with weak legs, having some increased tone (spasticity) is helpful as it allows people to stand or walk whereas the weakness would otherwise be too much to manage on.

Pain treatments depend on the cause. Stiffness or spasms will respond best to anti-spasticity agents. Burning or hot/cold like sensations may respond to gabapentin, pregabalin or some of the antidepressants (duloxetine, desipramine, amitriptyline, nortriptyline). Pain related to sitting in the same position will respond best to regular changes of position, seating review or simple painkillers like paracetamol or anti-inflammatories like ibuprofen.

Cynthia: My legs are weak and heavy and spasmy stiff. The right one is worse. I have tried physio and gabapentin and pregabalin, but none of these worked. I have also tried antidepressants and again these have not worked. I am finding walking more and more difficult now. I do try to move around a lot during the day, even go for a little walk up the garden with my stick, but it seems to be worse afterwards. I also have the burning hot sensations in both knees and have numbness in both feet.

Helena: I don't really suffer from problems all the time but seem very affected by cold and heat. For example, if I go to the gym and run, my right leg will feel weaker as it gets warmer (nothing wrong with left side so far). But if I step outside and it is very cold it feels like a tight grip over the top of my thigh. It makes the leg stiff until it warms up again from walking. I am not currently on any medication. Is this common?

Jon & Jenny: Yes, these symptoms are quite common. Increasing symptoms with increasing heat, for example through exercise, is often reported. Other people find their stiffness in particular is often worse in the cold. We don't yet understand why different people respond to temperature in different ways.

Some practical tips for managing this that you could try:

Trying to keep cooler while exercising, eg using a fan / drinking iced water / having a cold shower before or after you exercise (lots of these tips are available on the MS Trust/Society information leaflets on exercise).

Similarly in relation to the cold: try to keep warm, particularly around the affected leg. Some people find garments such as leg warmers / neoprene garments useful (there is no scientific evidence for this but people do say this can help).

Helena: Thank. I guess I could start a new trend with a leg warmer on just one leg ;).

Hellms: This is a terrible thing to say but I have lost faith in my hospital team. They can't get me better and the consultant's secretary, through incompetence and not giving a damn, missed a page for the DVLA and almost (seven days to spare) left me unable to drive. I have progressive MS. It's not just the disease we contend with! Sorry this sounds a bit bitter.

Bill: It's the killer part of this thing, isn't it, Hellms. Before MS most of us used to see treatment as a way to get better. Now it's a way to not get worse - or at least to get worse slower. Coming to terms with that took me a long time. Unhelpful people in the health service can't help at all, though I must say my team has been great.

Hellms: Thanks Bill, it does seem such a struggle but managing is what we do most of the time.

Crazy idea about exercising in this winter weather - Nintendo Wii. If nothing else, it may make you smile. I balance on the 'wobble board' using two walking sticks. I firmly believe that exercise is what we need to do - it actually helps the spasms. It also gives US a bit of power/control.

Simon - MS Trust: A Wii isn't that crazy an idea and people are looking into its value for people with mobility problems. We had an article in Open Door (August 2008) about a woman who used one to exercise. She'd played tennis when younger and liked the fact that she could prop herself against the sofa and bat a virtual ball around.

Hellms: I am on pregabalin and baclofen but if I increase the dose I am a zombie. Sometimes I think we get carried away with MS and paracetamol and ibuprofen can help. Just a thought. By my name you can tell how much I love this condition.

Phil: I have spasticity in my legs especially the right one. It gets worse as the day wears on. I used to take baclofen but when I asked my GP if I could up the dose he said 'yes but watch the side effects!' He then read out a list of side effects including 'effect on bowel movements ie erratic'. I need erratic bowel movements like a hole in the head! Any cure/alleviation for those? In the meantime how do I overcome the rigidity in my right leg?

I am 77 and have had primary progressive MS (and my wife suffers from it!) for the last 40 years. The older I become the more progressive does my MS become.

Jon & Jenny: Not potentially great side effects. However, individuals respond in very different ways to medication, and to baclofen, and it may well be that you do not experience these side effects. Since rigidity seems to be a real problem for you we would suggest you do go back to your GP and discuss this. Bear in mind that other anti-spasticity medications are available eg tizanidine and it may be that these are a possible alternative should the need arise.

Sandra: At the MS Society here we have access to a vibrogym that intensely exercises muscle groups. It was developed by NASA to exercise astronauts. I have found that the most effect is for my general fitness but also for the stretching exercises for my right leg particularly good.

Angie: I agree with you, the vibrogym helps my legs immensely. I have one at home and use it twice a day - morning and evening - and it reduced my spasms greatly.

Bill: Were you exercising before the vibrogym, or has having had the machine made you do more stuff? It's a pricy bit of kit and some of the stuff I've read seems to say it's not much better than just exercising without vibration.

Angie: I never used to do much for a few years when I was first diagnosed due to fatigue. But with the vibrogym I just have to stand and let it do the work. After a ten minute session I can walk up the stairs like a normal (you know what

I mean) person, one leg on each stair. I also take LDN which has helped other MS things but that's for a different chatroom.

Sandra: I was not able to walk around the block for a year or so before but now I can without too much stumbling and fatigue... although I still need a few cups of tea and a sit down. South Australia MS Society had one donated by a kind sufferer who had had great benefit, so I visit most Mondays. It keeps me in fine fettle for rest of the week. There are also regular gyms out there that have them, so seek them out.

Sandra: Angie, I am so glad to hear you get benefit as well. If I did not have access to one I would seriously think about taking out a loan to make it happen. What price mobility especially when you are self employed like me.

Jon & Jenny: You mention Bill that the vibrogym is expensive. Are you buying this yourself or accessing it through a leisure centre / physio gym?

Bill: I'd seen adverts in some of the MS magazines. Hadn't tracked anything down locally to try out, but maybe I should go and have a look.

Simon - MS Trust: Some of the MS Therapy Centres have vibrogyms, as well as a range of other things, often including physio. You can find your nearest Centre on the map of MS services.

Jon & Jenny: Interesting effects that others have reported with the vibrogym, clinically and in scientific papers. How long do the benefits last for, how often do you find you need to use it?

Sandra: I use the MS Society here in South Australia once a week for half hour. Initially it seriously fatigued me for the rest of day but for the rest of week I was stronger. Now it drains me for about two hours and I just sit and do admin for that time. Then I'm up and about with a bit of a limp. Rest of week I stretch, do yoga, push ups, triceps dips etc. Helps keeps me positive. Nothing like self determination!

Angie: I use it twice a day, seven days a week. My legs feel lighter and I have no twitches for up to four hours after each session. I think if I can feel like someone who does not have MS even for a short while then I'm as happy as Larry.

Dean: I have intermittent spasms. My neurologist wants to prescribe tizanidine and I am afraid to take it due to all the possible contraindications and the worsening of my other MS symptoms eg blurred vision, vertigo and dizziness. I take moderate doses of pregabalin, amitriptyline and sertraline for pain and chronic fatigue. Is there anything you can advise, please?

Jon & Jenny: Not everyone experiences all the potential side effects listed. Discuss this with your neurologist or nurse specialist. With careful monitoring of your symptoms and how they may change with your medication, you should be able to avoid any marked long term increase in symptoms.

Dean: I am going to try tizanidine, and if my other symptoms worsen I will stop taking. Whilst the spasms are a pain for me they are quite a problem for others. When I shake and flex my legs it can be dangerous as my leg is 37inches long. And you would be put off by the bewildered stares of people everywhere, though if it causes me to laugh I wet myself. Thankfully my carers and wife understand (if not amused!).

Andy: Stiffness is one of my main MS symptoms. If I could just ease it off I think I would be able to achieve much more. At the moment I take six baclofen tablets per day and one gabapentin. It should be three gabapentin but they just put me to sleep. Can you suggest anything else I could speak to my doctor about please? It may be that my current tablets are working but if they are then I dread to think what I would be like without them.

Val - neurologist: If the baclofen is working for you and not causing side effects I would keep things simple and increase the dose gradually. You say you're on six tablets, so that's 60mg a day. The maximum dose we use is 120mg, so you may just need to go up on that and forget the gabapentin if it doesn't suit you.

Jeff: I have primary progressive MS (diagnosed last year) and recently I'm suffering extreme stiffness when I am very tired meaning that I cannot walk at all until a long rest or sleep. Is there any medication to provide instant relief so I can still walk? Is this fatigue?

Jon & Jenny: There could be different things going on here: fatigue, increasing weakness with prolonged walking, and it could be that your pattern of walking may change as you walk further and this aggravates your stiffness.

You are right that medication may help go some way to helping with this problem. However, given that a number of factors may well be contributing to your walking difficulties, we would also recommend that you get an appointment to see a physiotherapist to assess exactly what is going on and to give you some advice on how to manage this.

Millymole: Does anyone else have leg spasms when they need to go to the loo? I often have a urinary tract infection (UTI) which makes my spasming worse but know when I go to the loo it will improve. They also spasm when they get too hot - I have to keep legs out of the duvet when I sleep. Also my feet now sometimes vibrate when my legs are spasming - this is a new thing. Does anyone else have any of these reactions?

Bigbird: Yes, I have spasms when I'm on the loo. Such fun.

Sandra: I would seriously consider woollen blankets. That way you prevent overheating. Also I wear layers that I can discard if required. I live in South Australia but on the edge of a desert so gets very cold in winter.

Bill: I definitely see spasms worse when I have an infection, and do get to enjoy infection in the form of a UTI more than I would like.

Jill: Sandra's idea of layers is good advice. I find even small shifts in temperature can do big things to my MS, so having the ability to control it to some degree is a help.

Alastair: Spasticity is more prominent first thing in the morning (in my case) on getting up. I do stretching exercises in bed in an attempt to prepare me but this will often as not bring on a rigid locking of my right leg. This eases eventually making getting dressed and going downstairs possible. During the day, the

longer I sit the more prominent the spasticity when I get up to move. Are there some muscles here I need to work? Wonderful things that mobility scooters are (I've had mine for three or four months), can they make you lazy?

Christy: My herbalist said that that magnesium is good to stop cramp but you need to take it at night as it doesn't have a long action. So I have moved my calcium/magnesium supplement to take it in bed now and have not had the problem since I started that... but it is colder. I now sleep with a sheet under my duvet and when the twitchy legs start, I get the affected leg out from under the duvet with just a sheet - cooling down seems to help.

Jill: Christy/Alastair - what you say ties in with the comment earlier about layers and controlling temp.

Bigbird: Has anyone else tried Botox for treatment of spasticity. I have injections about every five months (I have to self fund as my PCT says there is no clinical need). I find it helps with the spasms too.

Simon - MS Trust: Open Door had an article on botulinum toxin (Botox is a brand of this) a year or two back.

Bigbird: Thanks Simon. It was my neuro-physio who recommended it. NICE also recommends it but getting the PCT to pay is a different matter.

Chris: I tried Botox and found in the short-term it helped briefly.

Simon - MS Trust: Quite a few people have been talking about drugs. A large topic, I realise, but could you give a brief idea of the role of rehab and physio in the management of spasticity? Maybe you could talk about approaches to spasticity management that don't involve medication.

Jon & Jenny: We can broadly summarise non-drug approaches as:

An assessment of someone's spasticity over a 24 hour period is important to enable the development of a management program.

Management may include:

- Avoiding noxious (eg painful) stimuli - such as tight splints / bladder infections / skin breakdown/ in-grown toe nails/ tight fitting clothes. Check out these in the very first instance if you notice your spasticity getting worse.
- Posture - posture can impact significantly on spasticity and spasms. Good posture will also prevent / minimize discomfort in the back and legs.
- Sleeping positions - often people feel very stiff when they wake up first thing in the morning. Looking at your sleeping posture can be helpful in minimizing this. There is a range of equipment such as T rolls and wedges that can help people who have more severe spasticity / spasms. Both your MS nurse and your physio / occupation therapist will be able to offer you advice on this.

- Movement - effortful movement can trigger spasticity - sometimes things as simple as pulling up on a table when trying to stand up can aggravate spasticity / spasms. Identifying trigger factors such as these can significantly help.
- Fear and anxiety can aggravate spasticity / spasms. It important to feel safe and confident while moving while independently (eg aids can be helpful to improve confidence in your balance) or when relying on someone else for help (eg when being transferred in a hoist).
- Seating - seating systems and / or adaptations to wheelchairs can help to relieve discomfort and to optimise your posture, which will all help in the management of your spasticity / spasms.
- Mood - stress and low mood can aggravate spasticity / spasms. Your MS nurse will be a good contact point to discuss these issues and refer on when necessary.
- Tight muscles - stretching, splinting and standing programs can all be helpful in improving the range of movement in your joints and muscles. Some people also report that this also helps with reducing spasticity.

Bert: Does water in the body have an affect on spasticity and stiffness? Also, does swimming help? Dry skin creates or triggers spasticity. What are your thoughts?

Jon & Jenny: Yes dehydration can cause cramps and presumably this may in turn aggravate spasticity although we are not experts in this.

Dean: I enjoy swimming regularly. The water makes me feel buoyant and relaxed. However, I frequently go into spasms once I am out of the water. Similarly physiotherapy triggers my spasms. Everything I do to exercise does me good but I hate the spasms which are painful and exhausting. I think I will try to access a vibrogym.

Jon & Jenny: Some people find the buoyancy provided by the water can help to facilitate movement and thus decrease spasticity / spasms. You may have to be careful about the temperature of the pool as warm water can cause people to become fatigued. You are also right in highlighting the need to check skin and factors that could trigger spasms. If you are keen to try the vibrogym then try to access it via an MS centre or a local gym, as they may not work for you.

Christy: Dean, do you find the spasms are worse on days you do exercise? I do. The days I just stay at home and do no exercise I am less likely to get the spasms in the night. But I want to keep fit.

Simon - MS Trust: Christy, have you seen the exercises pages? These were put together by a physiotherapist and may have something that helps you balance fitness and avoidance of spasms.

Dean: Christy, yes, I always more spasms on days I swim or exercise. Thanks to all - this chatroom is very useful.

Liz: I have spasticity in my legs. I have tried a very low dose of baclofen but it made me very weak. The consultant at the rehab hospital wants me to try tizanidine and wants me to go into hospital for four to six weeks? Does anyone have any experience of the drug?

Val - neurologist: The fact the baclofen made you weak probably means it worked - I guess the stiffness was helping to keep you up. Tizanidine is unlikely to work any better unless the 'weakness' was more of a generalised feeling and not your legs becoming weaker. Maybe better to try a lower dose of baclofen. Going in to hospital is, I presume, a rehabilitation admission, in which case this may be a really useful thing to do. It allows you to have intensive therapy to help strengthening but also allows for retraining, perhaps with walking or transfer strategies. I'm sure you'll be allowed home for weekends!

Bill42: I take tizanidine several times a day and clonazepam at night. I'm having difficulty working out how much to take and when to take it. I tend to take it when I feel my legs are very stiff. Should I take it regularly spaced or as needed, and how bad should I feel before I take it.

Val - neurologist: It's always best to try and prevent problems rather than try and treat them once present, so it's definitely best to take tizanidine regularly rather than wait for things to be really bad.

It's useful to work out when are the bad times for you and then pre-empt them. For example lots of people are really stiff first thing in the mornings, which makes washing and dressing really difficult, but they still struggle through this time before taking their tablets with breakfast. I would advise to keep a glass of water and the tablets next to your bed and take them as soon as you wake, then perhaps wait half an hour before getting up so they are starting to take an effect.

Don't forget with tizanidine you need to have your bloods checked from time to time to ensure your liver is not being affected. Also look out for 'postural hypotension' with tizanidine. This is often overlooked but it can drop your blood pressure on standing making you feel dizzy and out of it.

Hope that helps.

Laurence: Wondered if there's any info on, or anyone has any experience of using, a TENS machine? Hoping it may help relieve MS stiffness?

Jon & Jenny: We are aware of a few scientific studies that show that TENS can decrease spasticity but we have limited clinical experience with this.

Simon - MS Trust: There are a few references to papers on TENS and spasticity in MS in the resources section at the end of this transcript.

Audrey: I suffer from extreme pain from spasms. A few years ago I took part in Sativex trials at Barts and it had such a beneficial effect. My GP thought it highly amusing that a woman of my advanced years should be taking cannabis, but refused to try to obtain it for me. My MS nurse is going to inform me when/if the local PCT will fund it for me. Surely, if drug companies reduced the price of drugs, then more PCTs would fund the drugs for the sufferers and everyone would be better off!

During the past 11 months I have had an excellent course of physio which has increased strength in legs and I have been referred to Active Lifestyles Gym.

Howard: You may have touched on one of the issues. Sativex is cannabis which is therefore a 'bad thing'. This view ignores the fact that MSers want it for a therapeutic effect not to get high. It also seems to ignore the fact that stuff not that far removed from heroin is commonly prescribed on the NHS to people who need it.

Bigbird: It was my understanding that Sativex isn't cannabis but a cannabinoid derivative with all the hallucinogenic bits missing.

Geoff: I think the big advantage with Sativex would be that you know what you're getting and can control the dose, whilst you never know what you're buying from the shady men around the back of the station.

Bert: I found that when I have spasticity and cramps going on, the elliptical machine will fatigue my legs and the problem goes away. Is this a wise thing to do?

Jon & Jenny: Do you mean you get spasms when using a walking machine in the gym or does the machine fatigue your legs and that then gets rid of the spasms ?

Bert: Yes, if I'm sitting and legs start to spasm or feel restless, by getting up and going on my elliptical machine for ten minutes this seems to get rid of the problem.

Jon & Jenny: Going back to you first question; is it a wise thing to do? I think there may be a trade off between getting rid of your spasms and restlessness symptoms and tiring yourself out too much so you find other things difficult to do. If you are not getting too much fatigue and it helps to manage your spasms, then great. And you have the added benefit of the exercise.

Chris: Can share on the appropriateness and pros and cons of a baclofen pump? I've taken oral baclofen for years and feel little effect. I have serious leg spasticity and stiffness. I don't hear much about it here in Hong Kong.

Carmel: I highly recommend an intrathecal baclofen pump to all. My pump was inserted in September 2009. I used oral baclofen for many years but then got a gastric ulcer. After a gastroscopy, the gastrologist said the ulcer was as result of baclofen. When I stopped the medication I started having spasms until, after 18 months, I had pump inserted by Dr Stevenson. Now I have very occasional spasms. Thank you for making my life so wonderful.

Val - neurologist: Good to hear from you Carmel.

I think the baclofen pump is a really useful strategy to know about. For those people who can not manage their spasticity well enough with tablets or who experience side effects such as drowsiness or fatigue, it can be fantastic. Although an invasive treatment requiring an operation to implant the device, it then only needs refilling (through a needle like a blood test) every six months and no taking tablets. Anyone interested in learning more should discuss this with their neurologist.

For those of you who are walking, don't be put off by people - even doctors - telling you it will take you off your feet. With careful selection (some people are just too weak and need significant spasticity or spasms to keep them walking) people's walking can be improved. Just ask Carmel.

You do need to be near a centre that has the expertise to manage pumps, so not sure what the provision is like in Hong Kong. Medtronic are one of the leading suppliers so it's worth checking out their website for local providers.

Simon - MS Trust: Carmel, how do you find living with the pump fitted? Did it feel heavy or uncomfortable at first?

Carmel: I must be honest, I was not aware of the pump at the start but did not sleep on my right side. I still use a T-Roll and therefore sleep on my back. I required trousers that were not sitting on the waist (the fashion last year was high waist) but now I can wear whatever I decide. The pump sits quiet deep and does not feel heavy.

I love gardening so when I try to dig, I can only get down so far on that side as the pump is in the way. That is the only time I am aware of it. It's well putting up with that for the better quality of life.

I am 60 now so do not wear very tight fitting silk. I guess with that you might see the bump. I carry card when going through scanning machine at the airport, though as yet I have never set off the alarm.

Emma: The muscle in my arm has spasms which prevent me from being able to lift it above shoulder height. I take baclofen at night for painful spasms but is there anything that I can take which would stop this? It would feel so good to be able to wave my arm in the air.

Jon & Jenny: It would be important to understand the cause of the arm spasms. Are they preceded or triggered by pain in the arm? If so targeting the cause of pain may be important. Exercises may help to strengthen the arm. Localised treatment of spasticity within the arm may also be useful.

Emma: As soon as I lift my arm up my muscle goes stiff. It was first thought that it was a frozen shoulder, but it's not. I get pain at night time with spasms but my muscle just goes so tight I just cant lift my arm up and neither can anyone else. I also get spasms in the whole arm when I get cold or get emotional. I go to aquatherapy twice a week. Initially I couldn't use it at all and physiotherapy was no good as as soon as someone told me to do something my arm seizes up. But at the MS centre at Saltney they have a vibrogym and they put pads on it and this got my strength up. I think it's possessed!

Jon & Jenny: It sounds like it is a mixture of things going on here. If no one else can lift your arm it may be that it is stiff in the joint and/or the muscles. A

program of stretching and exercise would usually help with this. The fact that the arm tenses up when you are emotional or cold suggests that spasticity may also be a problem. It might be that a review of your medication is required to see if you need to change the dose and/or timing.

Teresa: I get severe spasms at night. I can't control legs and they shoot out uncontrollably. I also am experiencing flexor spasms. I seem to be weakening on a daily basis and dread going to bed at night. I have tried baclofen, but it seems that the more I take the more my body needs, and I still wake with what seems even more violent episodes. I have tried gabapentin and tizanidine and don't like the effects of either. I had high dose steroids last year which helped the less severe spasms I had then, but it seems since the steroids, and in the period after they wore off, my spasms worsened. I am so miserable. It seems that all the medications get into the system and the body craves more and more. I take clonazepam at night in desperation so I get to sleep but the doctors and neurologist suggest getting off it because of the addictive nature of the drug. And I still spasm as soon as I awake after lying in the same position that I go to sleep in. I don't move at all and am obviously so stiff. I don't want more steroids but my neurologist says that's all he can offer. Please help.

Val - neurologist: Theresa, that sounds awful. Night time positioning is really important to try and relieve the stiffness - do you use a T roll or pillows? Your community physio could look at this with you. It's also worth checking that your mattress is appropriate.

I wouldn't worry about the addictive nature of drugs. Very few people develop tolerance (meaning their body needs more and more) and taking clonazepam at night is a very good strategy.

If things are that bad you should discuss intrathecal therapies (baclofen or phenol) with your neurologist. There is no reason to be suffering like that.

Carmel: For those with spasticity, I found a T-roll at night to be extremely helpful. You can also buy a blow up pump to take on holidays.

Joanne: My legs are very stiff and don't lift. Why then, when I wear tight fitting painful shoes that touch a nerve, does my leg lift? Also, my right hand is getting a lot weaker. In the morning when I wake it's clenched so tight into a fist that it's very hard to unclench it. Would exercises help with this?

Jon & Jenny: Different sensory stimuli such as a full bladder or tight fitting clothes or shoes can often trigger a spasm. It sounds as if this is what is happening in your case. We would suggest that you do not wear tight fitting shoes as these will aggravate your spasms and spasticity which will become counterproductive. Your legs are not getting stronger with this repeated movement it is purely a reflex being triggered.

Joanne: Ok, thank you. My spasticity is definitely worse when I have a full bladder.

Jon & Jenny: Three are a number of things you could look into for this:

- A stretching and exercise programme
- medication
- a review of your sleeping positions.

Your physiotherapists and doctor should be able to help with this.

Deb: I am inquiring about these certain nutrients for MS spasms and stiffness:

- Gamma-amino butyric
- MSM
- Threonine
- Anthocyanidics

Geoff: Following Deb's question, is there anything in the alternative/dietary/complementary arena that might have an effect on spasticity?

Jon & Jenny: There are many things that potentially could be useful. For example, techniques that help to reduce anxiety and help people to relax may help to decrease spasticity, as we know that spasticity can increase with anxiety / stress. Some massage related techniques could also help to loosen stiff muscles in a similar way to stretching. Interventions that promote body awareness and control of movement such as yoga or Tai Chi have also been reported to be useful. The difficulty about recommending something specific is that there is little or no scientific evidence from clinical trials that they actually work.

Geoff: Nothing in supplements or diets then?

Val - neurologist: I don't know of any evidence that nutritional supplements can help spasticity I'm afraid. As I'm sure you know, increasing fish oils, Omega 3 and 6, has shown a trend to improvements in MS but no other supplements have. Moving and stretching the key thing here.

Mag: I have tried and used many of the approaches above and they help me in different ways for different types of spasticity. Three of my non medical approaches are undiluted lavender oil applied to the tight muscle, acupuncture when I can afford it and, bizarrely, eating a cube of undiluted jelly helps when I have those light twitches which keep you awake!

Geoff: Eating lumps of jelly is the sort of treatment I want more of : -) Childhood habits die hard.

Val - neurologist: I love the idea of jelly cubes- could save the NHS a fortune!

Debi: I suffer with muscle stiffness which tends to get worse when my right leg starts to drag at the end of the day on the 15 minute walk I have to get home from work. I do stretches and go to the gym as often as I can to do aqua aerobics and the exercise bike. What else could I be doing to alleviate this?

Jon & Jenny: It sounds like you are managing this really well. However, one other thought we have is that if your leg drags due to the fatigue in the ankle muscles that lift your foot up, then simple aids such as the foot up splint can be really helpful for some people. The splint need not be worn all the time, just when you get tired. There are a whole variety of products on the market. Either your physio or local mobility centre could advise you about these.

Val - neurologist: As well as the orthotics route, foot-ups etc, you could ask your therapist or neurologist about FES (functional electrical stimulation). This is now NICE approved for use in MS and can be very helpful especially with foot drop which fatigues.

Simon - MS Trust: We have a factsheet on FES and FES services also appear on the map of MS services.

Joanne: My neurologist said the FES wouldn't benefit me so the splint is my only other option. My foot splint really helps with my right foot but I can't find any shoes or boots its fits inside due to my right foot being quite a bit swollen. I'd be grateful of any advice or websites?

Simon - MS Trust: The Disability Living Foundation (DLF) is a charity that produces factsheets and information about a wide range of equipment and products, including one on footwear.

Jon & Jenny: Sometimes it can be difficult getting a foot splint and the foot into a shoe. Some people have to get a shoe the next size up, although this can be expensive. If it is a splint that goes up the back of the leg then putting this in first and sliding the foot in like it is being eased in with a shoehorn can help. Make sure though that the shoe and foot and splint are not too tight as this could aggravate any spasticity or spasms. Keeping the feet up when sitting down and wearing supports can help to reduce swelling in the foot.

Heidi - physio: With regards to shoes it may be worth a look at www.cosyfeet.com. They are shoes specifically for bigger/swollen feet. Historically they weren't very attractive but have definitely improved.

Joanne: Thank you, that's very helpful : -).

Anne: My husband has had MS for nearly 40 years. He still has some mobility but has very stiff and heavy legs. He takes tizanidine hydrochloride 4mg - four tablets a day - for spasms and diazepam 5mg at night to help relax him and help him sleep. He has been taking this medication for many years. They do control the spasms, but make him sleepy.

My question is: What are the side effects of taking this drug over a period of years, and has an alternative been developed? His cognitive thinking is very poor and I have often wondered if this drug affects this aspect of his illness.

Val - neurologist: There are no real problems with taking the medication for years but he should have a blood test once a year. You're right that they could be affecting his thinking skills and tiredness, though unfortunately so can the MS. Often people don't realise how much the drugs do effect them until they come off. If his spasms are totally controlled, it may be worth reducing his daily dose by 2mg and see if there's any difference. If not, after a week you could pull out another 2mg and see what the minimum he can cope on is. That way you minimise any possible side effects. There are other options - baclofen and gabapentin - but both can cause similar effects, so it depends on how bad things are as to whether you want to risk rocking the boat. If he is very sleepy or spaced out, then of course you could consider a pump to avoid systemic side effects.

Simon - MS Trust: Mostly people have been talking about spasticity and spasms in their legs. Are symptoms in the hand and elsewhere around the body common and do they pose different problems for management?

Heidi - physio: Spasticity and spasms can occur in the arms too, especially causing movements such as bending of the elbow or clenching of the hand.

The first level principles of management are the same with regards to looking at:

- identifying triggers
 - checking posture of upper body generally as this may influence the arm and hand
 - trialling resting postures that discourage those abnormal movements including using splints.
-

Samir: I often have tremors at night when trying to sleep.

Simon - MS Trust: Samir's comment reflects one sent in from Carol, who said: is there is anything to help the shaking I have? My doctor says there is nothing but, I wondered if anybody else has shaking that has found something that does help.

Ruth: I measure my shaky moments by how easy it is to switch off the burglar alarm and punch in my pin number. But I persist regardless in the hope that using the fingers helps and it will stop the spasm by pressing on something. I have tired to take up knitting again but my hands ache very quickly.

Val - neurologist: Difficult to know what to advise about the shaking. If this is affecting the hands, it may well be ataxia rather than spasms. This is notoriously difficult to treat, though sometimes propranolol can help. Other options include gabapentin or clonazepam, but you need to be careful they don't cause sedation.

Posture is really important for upper limb tremor as, if your trunk isn't adequately supported, the arms shake much more. A physiotherapy or /occupational therapy review would be really helpful.

If the shaking is in the legs, it might be clonus - a rhythmical tapping of the feet. This is best helped by doing some calf stretches, though sometimes drugs such as baclofen can help.

Heidi - physio: With regards to the tremor issues at night, I guess we would need to be able to distinguish whether they are spasms or a separate tremor as this would help to work out possible medications that could be trialled.

For either though it would also be worth exploring different positions for sleeping or for that problem part of the body. Sometimes having that part of the body more supported can help. Also worth trialling stretching that part of the body before going to bed, in the direction opposite to the way that it tremors. A physiotherapist can advise better on this after an assessment.

Ruth: I take pregabalin as the gabapentin stopped working. I was taking up to five a day in a bad spell and baclofen 45mg a day. Since I had a holiday in Majorca, my symptoms have improved and I have reduced pregabalin to two a day and baclofen to 10mg, which is practically of homoeopathic proportions. However, if I miss 5mg, my legs stiffen up. It seems ridiculous that 5mg can make so much difference.

I will stop waffling, but I bought a light box thinking that if vitamin D does you good, then the extra light in these gloomy days might help. Do you think there is any substance to this idea?

Val - neurologist: You're right, even 5mg of baclofen can make a difference. In fact if I'm worried about treating someone's lower limb spasticity who is struggling with their walking, I will start on just 5mg twice a day.

Light box - no harm done but most of us will be getting enough sunlight even on winter days. Taking a general multivitamin with some vitamin D/calcium in is also a reasonable idea.

Diana: My feet are so tight I feel as if I have string tied round and round them. At night I take co-codamol to get me to sleep. If I wake in the night, I sit and play with my DS Lite for an hour till the pain lessens, taking more co-codamol. I also take sleeping tablets to knock me out. The theory is that I will be so dozey, I will sleep, rather than being awake all night with pain. This has been going on for many years. I cannot tell if I am wearing shoes and socks or not as my feet feel so tight. I wear Cotton Traders beach shoes all year round or cheap Ugg type boots in winter.

Val - neurologist: That sounds like a neuropathic type pain rather than spasticity. Have you tried gabapentin, pregabalin or one of the tricyclics such as amitriptyline?

Diana: I am totally spastic as well and have to be helped to sit up and to bend my back. Sometimes I am in tears with the pain in my legs and feet. I have tried all the drugs mentioned in this chat room and a few others. I had bad side effects and digestion problems. Currently per diem I have five baclofen, four duloxetine, six dantrium, four Dioctyl, one Vesicare, five plus cocodamol, one Movicol, one nitrazepam (sleeping tablet). Tried for Sativex. My neurologist cannot prescribe, my GP cannot prescribe. I even had an article in the paper (East Anglian Daily Times) about the post code lottery situation. Nice photo.

Val - neurologist: Have you considered a baclofen pump?

Heidi - physio: Although it seems like a more neuropathic type pain, it may be worth trialling stretching your feet regularly or asking someone to do this for you. For example, pulling your foot back as far as you can to stretch your calf and sole of the foot. I would also recommend regularly bending your feet up and down and in circles to keep them stimulated, unless it makes the sensations much worse. If you can tolerate it you could also keep touching/stroking/rubbing the area too.

A physiotherapist or occupational therapist also needs to be come and assess you at home, in bed and the wheelchair. The posture of your body and limbs may also be influencing the spasticity and pains and there may be even subtle changes that could be made.

Diana: Yes you are right. I do get someone to stretch my feet when I can (I can't reach them myself). I have treatment for lymphatic drainage and I have massage (both of which I pay for myself). Other tablets I have tried are sertraline (not sure what this was for now), etoricoxib, tramadol and Coversyl.

Spasms happen during the day and can go on for an hour or so - one leg at a time. What helps most is distracting myself with painting classes or by using my PC and mail.

I have an excellent MS nurse who watches over me and who is able to prescribe. He monitors my medication, and my partner prints out a list every week and ticks off all my tablets. But the pain of muscles being permanently tight is quite unbearable, especially at night.

Val - neurologist: It sounds like you need a review in a spasticity clinic - this could be either done locally or here at Queen Square [National Hospital for Neurology and Neurosurgery in London]. If this is something you would like, ask your GP or neurologist to refer you. Sometimes it needs a combination of a physical management programme (positioning, stretching, moving) and drugs to make a difference. Ask your doctor to review your baclofen dose and/or consider whether you need a combination of agents to manage things.

Diana: Unfortunately, we do not have any physiotherapy for MS in my area. It is a scandal. I have bought myself a Motomed bike, which I use for 30 minutes a day and I can stand up using my Genie chair. Both these help me a lot.

Val - neurologist: You may find clonazepam would help more than nitrazepam at night. It makes you drowsy but also specifically reduces muscle spasm and tightness.

Heidi - physio: Using the Motomed and standing regularly are brilliant things to be doing. Sorry to hear you don't have access to physiotherapy. Assessment in a spasticity clinic is definitely the way forward for a thorough multi-disciplinary assessment and appropriate management plan which you will be involved in making.

Jeff: Do you know when fampridine will be available in the UK? I am aware that it has been available in the USA since January under the brand name Ampyra. I understand that it is likely to improve walking for those with spasticity problems.

Val - neurologist: I'm afraid I don't know when fampridine will be available in the UK. You're right, it will be prescribed to help walking but it does this by improving conduction (reducing conduction block) so won't necessarily relieve spasticity - although the two often go hand in hand.

Shelagh: Look at spasticity as a minefield. Avoid these three mines - not having hot baths; not standing on cold concrete; and keeping stress out of your life as far as possible. Identify potential triggers and avoid.

Diane: My spasms seem to occur when I need to urinate. Does this happen to anyone else?

Heidi - physio: Identification of triggers is very important. They may be very subtle triggers.

Examples are:

- cold or even heat
- bladder retention
- constipation
- any kind of infection whether of urine or a cut on a finger
- broken skin/pressure areas
- positioning and posture of body and limbs, especially of parts of the body you find difficult to move. The actual position or posture may have an impact or being in one position for too long may as well
- muscle stiffness
- patterns of movement eg the way you walk
- pain from any of the above
- fatigue
- poor sleep
- stress and anxiety - even every day life stresses

Cleo: There has been talk of Sativex earlier (and the difficulty in getting it). Accepting the illegality, do you have any thoughts on cannabis as a help for MS spasticity and pain?

Val - neurologist: If you're going to try cannabis then Sativex is obviously a much better way of taking it. Obviously smoking has its own risks, and with street cannabis you don't really know what you're getting.

Sativex has been shown to help 50% of people, the others being non-responders. Even then the effect is not dramatic. I suspect there's a small population who will be helped but it's not the wonder drug we all dream of.

Cleo: Thank you. I'd thought as much from what I'd been reading and it's so frustrating when the papers blow something out of all proportion and get your hope up unnecessarily. In the past I had tried the cannabis chocolate and found it had some effect - especially if taken before bed. But sadly the law caught up with them and beneficent illegality is still illegality.

Marcia: A general comment with regard to MS. I have been diagnosed with vitamin B12 deficiency. I have opted for taking tablets rather than injections, but find they make a great deal of difference to the strength of my legs. I wonder whether all people with MS should be advised to try taking B12?

Lisa - nurse specialist: It sounds as though you have found something that works well for you. Have you been taking the tablets for a long time?

Marcia: I have been taking B12 since the middle of January this year. As the tablets are not a recognized treatment by the NHS, my GP was not able to give advice about dosage and I have had to experiment for myself to find the dose that suits me.

Carmel: I have taken B12 injection for the last four years. It was weekly until about six months ago but is now three monthly as the three monthly dose is the only injection available. I would highly recommend it. I think it is what prevents my fatigue. I also take a vitamin D tablet every day and have my daughter on it also.

Marcia: B12 also help nerve pain for me.

Bert: My spasms hurt in the groin area when they are triggered off and I'm not able to lift my left leg very well. What exercise would you recommend?

Lisa - nurse specialist: I think Heidi would be best with the exercise recommendations but if you have a local physio who knows you, they would recommend a programme for you. Some people find they have to let the spasm ease before attempting stretches. Do you take any spasticity or pain medications?

Heidi - physio: When the spasm happens does the leg pull upwards or inwards or both? Do they tend to happen when sitting or lying down?

Bert: The leg pulls upwards and often when I'm sitting or lying down. I'm trying to strengthen the leg to lift up for walking but it feels weak in the groin. The elliptical machine doesn't strengthen the lifting part. I have taken baclofen but it seems to make me weak.

Lisa - nurse specialist: Baclofen can make you feel weak. Did you try a low dose or look at alternatives?

Marcia: I find Tizanidine doesn't weaken the muscles as much as baclofen.

Heidi - physio: Asking for a physiotherapy review would be worthwhile. They can then assess:

- your posture when sitting and lying as this may be encouraging the leg to pull upwards
- whether practising lifting your leg up is a good idea or not, it may be encouraging the spasm
- whether there is any tightness in your groin muscles which may be also encouraging the spasm
- whether there is an easy way for you to regularly stretch the groin to try to minimise the occurrence of spasms eg by standing in a good position or even by subtle pelvic movements when sitting
- whether there are other ways to help your walking without having to rely on lifting your leg from the groin

Have you identified anything that seems to trigger the spasm?

Lisa - nurse specialist: Also, maybe you need to establish whether the pain is triggering the spasm. If so, getting on top of the pain will help.

Bert: Thanks for your time, I'll talk to my physio. It's kind of one weakens the other. More exercises:)

Lisa - nurse specialist: Bye Bert, hope you get sorted.

Heidi - physio: Bye Bert. Make sure you ask the physio to look at the things I suggested. There should be ways of adapting what you are doing already without the need for more exercises.

Cleo: Is there much to choose between baclofen and tizanidine? They seem to be offered in that order and I've heard varying opinions on both from friends with MS.

Marcia: Baclofen didn't control my spasms but made me extra drowsy. Tizanidine work for me and legs felt stronger.

Lisa - nurse specialist: I think tolerance of any of these medications is quite individual but I suspect its unusual for people not to have any side effects. Sometimes a combination works well for people.

Val - neurologist: We tend to use baclofen as first line as you don't need any blood tests like with tizanidine. Some people say tizanidine is better tolerated than baclofen though I have to say in my experience tizanidine causes a lot of dizziness through low blood pressure which makes people feel yucky.

Diana: I have had a very stressful past two years. This definitely makes things worse. I was crying all the time and very depressed. I had become totally incontinent. I had an indwelling catheter fitted which really helped. I had had three Botox sessions before that, which were excellent at preventing incontinence, but it did not work for ever.

If my legs spasm it often makes my catheter leak. When I am being hoisted into bed at night time, my whole body goes into spasms and then my catheter leaks a lot, even though I may have been OK all day. Constipation also makes for spasms, but I have mastered this problem with Movicol and Peristeen. So I am in control of both these essential but annoying functions. Mostly, looking back, it has been a question of researching what is available, and finding the right person who can help. And not being fobbed off by various medical people.

One thing I did have was to be wired up in hospital to an electrical device which stimulated my leg muscles and somehow proved that they are OK, and it is the nerves themselves that are dead. It was strange to have someone move my legs when I cannot do it myself. I am not sure how I felt about this.

Lisa - nurse specialist: Hi Diana, it sounds like you have had a tough time of it. Bladder problems can be very difficult to manage and are often huge spasticity triggers. Hope you feel you are on top of your spasticity now.

Alison: I am a 52 year old lady who was diagnosed with MS in 1978 aged 19, five months before my marriage. I have two grown sons and was divorced two years ago. My most troublesome symptoms are spasticity in my legs and incontinence. The incontinence is managed with an annual visit to Queen Square [National Hospital for Neurology and Neurosurgery in London] for Botox. However, despite physiotherapy, tizanidine, being on a trial for a cannabis derivative, a visit to Bulgaria for CCSVI and just having started LDN, it's worse than ever. I am beginning to despair and don't know what else to do. I would welcome any advice.

Val - neurologist: I think you would benefit from a review in a spasticity clinic either locally or here at Queen Square.

Heidi - physio: Without going in to specifics of your spasticity problems, I would probably recommend requesting a referral to the spasticity clinic at Queens Square if you have been linked in with urology there before. This clinic can then fully assess all aspects of your spasticity and work out with you an appropriate management plan - whether that be medication or therapy related. They can also link in with the urology clinic as required to make sure everyone is thinking in the same way to manage both of your issues.

Lisa - nurse specialist: I think you need to establish if there any other triggers that are not being managed, such as: bladder, bowel, movement, positioning in chair or bed. When is it worse? What makes it better? The only medicinal treatment there for spasticity is tizanidine, maybe other options need to be looked at?

Fiona: I have only just started to have some spasms in my right foot and jerky movements in my leg sometimes when I stand up, as if whole leg has stiffened and then jerks. Now my right foot and ankle seem to be stiffening up. I'm not sure if this is called spasticity or is more the spasms - assume both go hand in hand?

Lisa - nurse specialist: You can have spasms and stiffness together. You can also get something called clonus which involves repetitive tapping of the foot when the ankle is stretched. Not sure if that's what you are describing.

Heidi - physio: When you stand up does your heel bob up and down making the rest of your leg jerk?

June: I am taking LDN and 0.5mg clonazepam. I still get twitches at night and leg spasms in the morning. The cold weather does not help with my limited 'few steps' walking. I have tried tizanidine and baclofen, neither of which helped. Is there anything else I can take that will help me? I have primary progressive MS and am 68 years old.

Lisa - nurse specialist: Have you tried changing the clonazepam dose? Also do you take anything in the morning before getting out of bed?

June: I increased clonazepam to 1mg per night but my leg muscles became weaker. I do not take anything before getting out of bed.

Lisa - nurse specialist: Often we find people take baclofen after they have struggled with getting out of bed and getting washed, dressed etc. Morning times tend to be most problematic because of various triggers such as being in the same position all night. Often we recommend a small dose of baclofen about 30 to 45 minutes before getting up, so the effect will have kicked in and morning spasms might not be so problematic.

June: Can I take baclofen as well as the clonazepam?

Lisa - nurse specialist: Yes, clonazepam is what we recommend for night time spasms as it has a sedative effect for sleeping but also it impacts on spasms. We don't recommend it during the day as it can cause drowsiness. Many people take clonazepam at night and are also on other medications but of course the effects need to be monitored.

Heidi - physio: In what way do your legs twitch and spasm - eg do they pull up towards you or push out away from you or pull inwards?

June: My legs and feet twitch upwards when sitting and my legs go into spasm and pull away from me when I get out of bed in the morning.

Heidi - physio: Even if you don't take any steps I would recommend that you stand as often as possible during the day, with support as required. The idea being to break up the flexed posture that you are in when sitting as the twitches seem to be going towards a sitting posture. Standing is also important to get weight through your legs which in turn can help dampen down muscles that are overactive. You may need a physiotherapist to see you at home to establish the safest and easiest way to stand regularly and to identify the best support eg rail on wall or need for a more supportive frame to stand with. What position do you tend to sleep in at night?

Lisa - nurse specialist: Have you tried changing your night time position?

June: At night I sleep on my left side with my legs bent slightly.

Heidi - physio: It may be worth trying your knees being more bent during the night and possibly with a little something between your knees? If possible a change of position during the night would be good too so that you're not expecting your legs to suddenly wake up after being in one position for hours and hours. It may also be worth trying slowly and gently moving each part of your legs in the morning when you wake up to help wake them up a bit before trying to get out of bed.

June: Yes. I have tried sleeping on my right side but I found it painful. Sometimes I can lie on my back.

Lisa - nurse specialist: I think the suggestions Heidi is making will help with managing the trigger of being restricted in one position overnight. Once this is managed you may notice an instant difference, perhaps a physio review at home would be good to look at positioning. Maybe keeping a diary of the most problematic times would be useful for guiding you in whether you need to pursue the medication option also.

Heidi - physio: If you can sleep on your back sometimes that is great. You may need something under your knees to prevent your knees being out straight. A physiotherapy assessment at home could also look at this and provide you with something to rest your legs on. It will be a busy physiotherapy assessment

looking at how to get you standing more and your positioning in bed! But should all hopefully help your spasms. Make sure to request they look at the things I've recommended.

June: Thank you very much for your help.

Simon - MS Trust: The book Are you sitting comfortably has brief information on using rolls to alter your position when lying down. This is listed in the Resources section at the end.

Jo: I am on a low dosage of baclofen - should I increase it for the spasticity? Does that improve by taking an increased amount?

Lisa - nurse specialist: Before adjusting any medications it is important to review and manage any triggers that might be causing an increase in spasticity. If these are well managed and there is no other obvious cause then changing medication dose is an option and can be very effective but needs to be monitored.

Louise: I have had spasms controlled with baclofen when having relapses. I have found regular stretches and physiotherapy mean I only take baclofen very occasionally now, which means I am more alert. Keep active.

Lisa - nurse specialist: Hi Louise. That sounds like it suits you when you have relapses and at other times stretching alone is sufficient. People can find these medications make them feel drowsy.

John H: I take baclofen for spasms and tegretol for tremors and was advised by my doctor to slowly increase the dosages until the spasms and tremors went away. I was on fairly large doses and they both started occurring at night. I read that you do not have tremors at night and if you do it is probably because of other tablets so I started to reduce the dosages of both with my doctor's knowledge. The spasms went away when I was on a very low dosage and I eventually stopped taking them altogether. I have found a way of stopping the tremors whenever I notice that they are starting. It took me some 2-3 months to perfect the system and basically it is all to do with controlling the subconscious mind.

By the way if I have spasms I can reduce them by the same method but I have not had enough practice to stop them completely. Slow but sure is the motto.

Jo: Is there anything that can be done by physio to relieve the pain I experience in my lower back on the right? Following a relapse I had earlier in the year it has been extremely difficult to achieve pain relief despite exercising at home. My legs become very tired after a short distance and I start dragging my leg so much that it is impossible for me to walk any distance for long periods.

Heidi - physio: Does the pain seem to be related to the way that you walk when you start dragging your leg?

Jo: Hard to tell if the pain affects walking or the other way round.

Heidi - physio: I would suggest a thorough assessment of your walking to check if the way you are moving is contributing to the pain. It's hard to tell without seeing you but you may even be a candidate for using a foot-drop stimulator to help lift your weak leg when it gets tired so that the quality of your walking doesn't deteriorate and you may find you can walk for longer. You need to find out if there are any FES (functional electrical stimulation) services near you. Where do you live?

Simon - MS Trust: The MS Trust has a factsheet on FES (functional electrical stimulation). The map of MS services also lists FES centres.

Lisa - nurse specialist: Have you established the source/cause of this pain?

Jo: No, it's just an awareness of what is happening rather than why.

Lisa - nurse specialist: I would suggest you establish what the cause is - speak to your GP or neurologist. Depending on the cause, that could be treated which may alleviate the pain and help you do more pain free. It may be a muscular problem which would be treated one way or could be neuropathic pain which needs alternative treatment.

Mike R: I've been on gabapentin and baclofen for twitches in legs, particularly at night, but have started on rotigotine patches (Neupro) up to 4mg at night, which work very well. Any less and I have extremely stiff legs in the morning, which is a down-side. My goal is to start Sativex - I've had MS for 27 yrs, now secondary progressive, but still relatively mobile.

Lisa - nurse specialist: This is not a medication we would use for spasticity normally but glad to hear it is working for you.

Heidi - physio: If you are experiencing more leg stiffness in the morning you may need to explore better leg positioning during the night, preferably in the position opposite to the way your legs tend to stiffen up. Change of position during the night is also important if this is possible.

Mike R: I tend to be a quiet sleeper, so don't move much. I do have an excellent physio stretching regime, so this alleviates the stiffness somewhat when I wake, but I am also noticing that weakness and spasticity are increasing since starting the Neupro - may be coincidental? Hence my wish to try Sativex.

Angela: I have suffered for about a year now with pain in my upper arms. It is worse when I try to raise the arms above the shoulder or stretch out for something. I have been to the GP and had two tests for PMR (polymyalgia rheumatica) but these were inconclusive. Does this sound like spasticity?

Heidi - physio: It doesn't sound like spasticity. If you try to lift your arms quickly what happens to your arms? In theory, if it was spasticity your arms would resist you trying to lift them and tense up. I would also suggest asking to see a neuro-physiotherapist who will be able to assess the way you lift your arms and work out whether the pain is more due to weakness, poor quality of movement or poor posture. They can also more specifically assess for spasticity.

Planethannah: I've had a new symptom in the last few months - spasms in thumb and ring finger of my right hand. During the night, particularly, they seize up, and when I try to move them on waking, they sometimes don't respond or are painful or snap out of the spasm. I am right handed and anxious that I'm going to lose the ability to use my right hand. Any advice would be appreciated. Thanks.

Heidi - physio: With this being so localised to your hand I would suggest a non-medication route first. You really need to see a physio or an occupational therapist and trial a resting splint for your hand to wear during the night to help keep your hand in an open and supported position. How does your right hand behave during the day? Are you able to open and stretch it out fully using your other hand or with assistance?

Planethannah: During the day sometimes my finger and thumb lock and then can be snapped open either with effort or assistance but with pain, which then lingers. I'm seeing my GP and MS nurse next week, and will mention your suggestions. I have felt for years that I need help with learning how to sleep comfortably (I'm 52) as I always wake up in pain, stiff, sore and now often in spasm. During the day I'm conscious that I'm carrying the weight of the residue of all that - for example mostly I just use my right arm to drive, because my left arm is too tired and sore. I have asked health professionals before now about learning how to sleep comfortably but have been dismissed with remarks about how relaxed we are when we sleep, as if that would preclude any further pain or pressure on painful parts of the body. The problems with my right hand are the most worrying that I've had since being diagnosed five years ago - without the use of it, I would/will lose my independence. Low mood doesn't really cover how it makes me feel.

Heidi - physio: As well as my previous suggestions re: requesting referral for a resting splint, the therapist will also be able to work out whether the culprit muscles in your hand need relaxing eg with botulinum toxin injections to prevent the locking. It may be though that using a splint at night and stretching during the day is enough to reduce the locking. If the locking can be reduced then the therapist can more easily work out if there is potential for improved movement and function in that hand. The tension and locking may have been preventing access to better movements. What position do you sleep in at night?

Planethannah: I can only sleep on my right side as I have chronic pain in my left shoulder and have never learnt to sleep on my back, despite trying. I have tried squeezing a small rubber ball or similar for a few minutes during the day, but all that seems to do is make my hands tired. I walk with a stick in my right hand.

Heidi - physio: I would probably recommend you stop squeezing the ball, just because it may be feeding in to the pulling in pattern of your thumb and finger. Or squeeze the ball less but you must make sure you stretch the whole hand outwards as far as possible after squeezing.

Obviously you need to use your stick but again this encourages flexion or a pulling in of your hand. Stretching your hand open and a resting splint (for a more prolonged open stretch) would definitely be advised. When on your side are your legs bent or straight? Do you use anything between your knees?

Planethannah: Your comments re my hand are helpful and seem to relate to what's going on. I sleep with my legs bent as if I'm locked like that. I have tried using cushions of various kinds between my knees, and also a neoprene brace, as well as raising the mattress under my feet. To be honest nothing really seems to make a difference. I've stopped gabapentin and venlafaxine also because they have no discernible effect. Resting splint and TENS sound promising. I'm not keen on botulinum, and stretching and OT such as knitting just seems to make pain and spasm worse. It's great to be taken seriously - the last neurologist I saw, in New Zealand, told me a lot of stuff but hardly asked one question.

Debra: I've tried TENS, but it didn't work for me - just made my toes curl up.

Heidi - physio: The thing with TENS being used for spasticity is that you use different settings from what you would use for management of pain.

Something else I've just thought of but don't know all that much about it is the use of acupuncture for spasticity. You would really need to see a neuro-physio who has trained in the use of acupuncture for neurological conditions.

Lisa - nurse specialist: Just to add to Heidi's post, with both acupuncture and TENS a person's skin sensory function needs to be considered and closely monitored. If they don't have normal feeling, skin damage can occur unbeknownst to the person using the treatments.

Planethannah: Don't know if other people with MS have found this, but acupuncture makes me cry with pain.

Lisa - nurse specialist: I can understand that as the pathways are not always normal and sensation can be heightened and out of proportion making treatment very painful.

John: Has anybody got any suggestions for either over the counter drugs or alternative medications that help relieve spasticity?

Lisa - nurse specialist: I am not aware of many over the counter treatments which directly treat spasticity. There are however plenty of things over the counter that will treat trigger factors and alternative therapies such as massage and exercise based therapies are good for everyone to maintain mobility and general wellbeing. Caution needs to be taken with massage related treatments because they can trigger spasm and pain.

Heidi - physio: I second what Lisa says. Also you need to bear in mind that massage often only has short lasting effects as it doesn't deal with the actual physiology behind what causes the spasticity and spasms in the first place. Prescribed medications aim to do that. One non-medication related option that some people find beneficial is using TENS on the areas affected by spasticity. A good neuro-physiotherapy or spasticity clinic assessment should help to identify factors that contribute to your spasticity and together you can work out a management plan.

Debra: I have recurring muscle stiffness in my legs, particularly at night. Sometimes this progresses to cramp, which makes me nervous about sleeping (I used to be a champion sleeper!) Now, I walk in the early morning but use a wheelchair at night. I'm 6ft 1" and I used to play competitive sports (so I have very defined calf muscles). Now I just take six baclofen per day, which seems to make no difference. What else can I do to improve my sleep and thus wellbeing?

Lisa - nurse specialist: Sounds like you have not explored other medications. Have you had a physio review with regard to positioning and movement?

Debra: I attend physio regularly (now once every two-weeks) and I am having specialist splints made to help me walk. This doesn't really help the cramps and sleeping though.

Heidi - physio: You need to talk to the physio about night time, specifically about the position you sleep in to see if the position may be feeding in to your muscle stiffness. There may also be specific stretches you can do by yourself before you go to bed to make sure your legs are as flexible as possible before being fairly still all night. When you have the new splints you may notice some difference at night if you've been able to walk during the day with a better quality. Other medications should also be explored, specifically at night time.

Debra: Thanks Heidi - OK will do.

Lisa - nurse specialist: I think you have lots of scope for medication alterations, especially at night time, so I don't think you should have to put up with sleeping difficulties.

Heidi - physio: Thinking about your hand, if you aren't keen on idea of botulinum or stretching, definitely try and get a resting splint. Also may be worth seeing if you have an FES (functional electrical stimulation) service near you as you may be able to use electrical stimulation for more active opening and therefore stretching of your hand. It may be a way of improving the movements in your hand too if the potential is there. Would probably recommend FES over TENS as there may be more to be gained by using it.

Simon - MS Trust: The MS Trust has a factsheet on FES (functional electrical stimulation). The map of MS services also lists FES centres.

Jim: Reading through, someone mentioned phenol earlier. I've not heard of that, how does it fit in?

Lisa - nurse specialist: Phenol is a treatment option used in very severe spasticity cases where a person may have no functional movement at all. It is a procedure that destroys nerve pathways so is permanent and not one that is considered lightly.

Simon - MS Trust: We're coming up to 7pm. That's the end of today's chatroom.

Thanks to everyone who has asked questions and shared their thoughts on spasticity today. And thanks to Lisa and Heidi and also to Val, Jenny and Jon who were online earlier in the day.

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

MS Trust Information Service - 0800 032 38 39 / infoteam@mstrust.org.uk

Books

- Are you sitting comfortably
- Spasticity care pathway

DVD

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

Factsheets

- Cannabis
- FES (functional electrical stimulation)
- LDN (low dose naltrexone)
- Sativex
- Spasticity and spasm
- Vitamin D

Website resources

- A to Z of MS - www.mstrust.org.uk/atoz
- Exercises for people with MS - www.mstrust.org.uk/exercises
- Map of MS services - www.mstrust.org.uk/map
- Staying active - www.mstrust.org.uk/stayactive

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

- Botulinum toxin - February 2008 pp 12-13
- Exercise with a Wii - A 63rd birthday surprise - August 2008 p 14

Contact the MS Trust to order publications or to join the Open Door mailing list. All publications are free apart from the DVD, which costs £1

MS Trust, Spirella Building, Bridge Road, Letchworth Garden City, SG6 4ET
01462 476700 / info@mstrust.org.uk / www.mstrust.org.uk

Other resources mentioned

Charities

- **MS Society**
0808 800 8000 / www.mssociety.org.uk
Exercise and physiotherapy - <http://tinyurl.com/mssoc-exercise>
- **Disability Living Foundation (DLF)**
a national charity providing impartial information on daily living aids
020 7289 6111
info@dlf.org.uk
www.dlf.org.uk

Commercial organisations

- **Cosyfeet**
Manufacturer of extra wide, deep and roomy footwear
01458 449035 / comfort@cosyfeet.co.uk / www.cosyfeet.com
- **Easycare Products Limited**
Manufacturer of the Genie standing wheelchair. These wheelchairs also available for other suppliers
01952 610300 / info@easycareproducts.co.uk / www.genie-standing-wheelchair.co.uk
- **Medimotion**
Supplier of the Motomed passive, assisted or fully active exercise system
01559 384097 / sales@medimotion.co.uk / www.motomed-medimotion.co.uk/contact.html
- **Medtronic**
Manufacturer of baclofen pump used in intrathecal baclofen therapy
01923 212213 / <http://tinyurl.com/medtronic-itb>

Papers on TENS and spasticity in MS

- Miller L, et al.
The effects of transcutaneous electrical nerve stimulation (TENS) on spasticity in multiple sclerosis.
Multiple Sclerosis 2007;13(4):527-533.
- Armutlu K, et al.
The effect of transcutaneous electrical nerve stimulation on spasticity in multiple sclerosis patients: a pilot study.
Neurorehabilitation and neural repair 2003;17(2):79-82.