



Sexual issues and MS

Chatroom

24 April 2007

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24 April 2007 – 10am to 7pm

- **Nicki Ward-Abel** – *MS lecturer practitioner (10am – 2.30pm)*
 - **Nolly Biggins** – *clinical nurse specialist (10am – 2.30pm)*
 - **Ruth Hallam-Jones** – *psychosexual therapist (2.30pm – 6.30pm)*
 - **Vicki Gutteridge** – *MS specialist nurse (2.30pm – 7pm)*
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This chatroom is an open forum and so the views expressed by participants are their own and are not necessarily those of the MS Trust.

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

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Simon - MS Trust: The chatroom is now open. Nicki and Nolly are online to answer any questions on sexual issues and MS that you want to ask

Steven: Good morning. I have a question important to both myself and my partner. Where has my libido gone? And how do I get it back?

Nicki - MS lecturer practitioner: Hi there, Steven. There are a whole load of reasons why your libido may have decreased, it could be as a direct result of your MS, but often it is due to all sorts of other reasons that the general population experience too. Are you in a relationship at the moment?

If you consider ways that libido can be affected perhaps you can relate to one or more of these. These are common reasons:

- fatigue
- worry that MS symptoms can affect you sexually
- financial worries
- problems sleeping
- worries that your body image is changing
- poor self confidence

Steven: Yes I am in a very loving relationship. I am prescribed tadalafil, which works excellently with the 'mechanics'. I want to want to make love, if you see what I mean. However, I only seem to want it about once a month. This leaves us having sex on my terms or not at all - which is hardly fair on my partner.

Nicki - MS lecturer practitioner: I see what you mean Steven, some people find that one thing they can do is to concentrate on their thoughts. You may already do this but...

Nolly - nurse specialist: Loss of libido in the true sense (reduced desire for sexual intercourse) is a common problem. Sometimes it is the body's way of compensating when there are problems with obtaining an erection or when fatigue or spasm make intercourse difficult. Medications can also play a part. It is important to talk to your GP or nurse specialist so that they can review your medication and perform some simple blood tests.

Debbie: I am an MS sufferer, diagnosed in October 2003 - I too suffer from loss of libido. Any tips on how this can be restored?

Nolly - nurse specialist: Debbie how old are you?

Debbie: I am a young 47 year old.

Nolly - nurse specialist: Debbie, you are a little young to be going through the menopause (this can decrease libido)

Nicki - MS lecturer practitioner: There have already been more than one question on libido so I will write down some things that people with MS have tried that have made a difference. Some of these are pretty straightforward but here we go.

They say that the most powerful sex organ is the brain! If that isn't turned on, then the rest of you won't be either. So one thing that is particularly important is to have lots of sexy thoughts and concentrate on what makes you feel sexy.

Some people find that setting the 'scene' if you like is helpful, if you are having a laugh with your partner and have had a good time together this helps. Some have to think sexy thoughts in their mind for a period of time, some think about it all day, others for half an hour or so, but you have to really tune your mind into it.

Jane: I agree with Nicki on the libido thing, getting your brain to stop thinking about all the cr*p in life and just to focus on a time/experience when you felt sexy really helps. Slowly building on that memory/feeling for a few hours can really help.

Nicki - MS lecturer practitioner: There are some simple games that you can do to charge up the environment, these can be obtained in some stores or on the internet. They can involve you playing a bit of a game where perhaps you are blindfolded and your partner kisses, touches you intimately and so on. You can then reverse the roles and you can blindfold your partner and so on. You may want to direct your partner in what it is you want them to do and give them lots of encouragement when they do something that arouses you.

One game one person told me is that he and his partner each write down five things that they would like their partner to do to them. They write these on post it notes and then fold them up. The partner picks one of them at random and then does what it is the partner is asking on the post it note! They say it works really well for them

Does anyone else have tips on games to play that they find helpful?

Lots tell me that to help libido it's really important to experiment with different ways of lovemaking. If what you are doing doesn't work for you, then it's worth trying out something new. I often find people I see don't actually tell their partner what 'turns them on' often they don't really know themselves.

I often ask the person to investigate their body. They can do this on their own or with a partner. If you look on the internet for 'body mapping' or 'sensuous touch' you will find a way of doing this, but basically its about you finding out where your erogenous or sexy zones are on your body that are not perhaps obvious, some find its their ears, their navel area and so on.

Steven: Nicki, Thank you - I will 'put my mind to it'. Hope you didn't mind me starting a thread here - it's just that after 11 years of sorting everything else out this is the subject that has arisen (excuse the pun) most lately and takes a lot of accepting.

Nicki - MS lecturer practitioner: Is there anyone on line who can share some tips they use to increase their libido?

Lucy: Not really a libido thing, but I can say the fact that Ann Summers and the like are on high streets and in respectable shopping centres makes it so much easy to buy this sort of thing without it seeming a bit smutty

Chris: What is tadalafil please? Never heard of it.

Nolly - nurse specialist: Tadalafil is one of the drugs designed to help obtain erections. You may have heard of Viagra this is a similar drug

Steven: Chris - Tadalafil is produced by Cialis. Strangely you often see their sponsorship banners around golf holes! Anyway my doctor prescribes them, only he is only allowed to prescribe four a month. I moved to these after Viagra didn't work

Chris: Thanks. Is it another name for Cialis or Levitra? Having said that, none of these three drugs help me getting an erection now - big problem!

Nolly - nurse specialist: With any of the drugs - Viagra, Levitra and Cialis - it is important that you are sexually stimulated or they won't work. How often have you tried them and did you have the maximum dose?

Chris: Yes, I think I have tried them all and all doses. The same goes for the Caverject, which I know is a completely different mechanism.

Nolly - nurse specialist: Chris, there are other treatments available. Vacuum pumps are now available on prescription. Vacuum pumps are cylinders that are placed over the penis. A ring has already been loaded over the tube. A hand/battery pump produces negative pressure resulting in an erection. The ring is then slipped of the pump onto the base of the penis and the tube removed.

There is also another injection other than Caverject which is due to be launched later in the year

Geoff: What is Caverject?

Nicki - MS lecturer practitioner: Caverject a drug that men inject in the base of their penis and it produces an erection.

Nolly - nurse specialist: It is injected 15 minutes or so before making love. It produces an erection that lasts for 30-60 minutes

Chris: Geoff, Caverject is an injection of liquid into the penis to make it erect within a few minutes. It sounds like a terrible torture, but actually it's nothing special and becomes normal. Similar to how intermittent self catheterisation sounded terrible but is now utterly uneventful

Geoff: Thanks Chris - put like that it doesn't sound so bad! :-)

Nicki - MS lecturer practitioner: Yes, well done Chris, whenever I explain Caverject to men they start to look petrified! I will tell them what you said! Hopefully this will encourage them to give it a go!

Nicki - MS lecturer practitioner: Nolly, I didn't know about a new drug coming out similar to Caverject, what will be the difference in it? Do you know its name?

Nolly - nurse specialist: It's called Invicorp. It has been around for a number of years but never launched in the UK. I was involved in the original trials. It is vasoactive polypeptide and phentolmine. Invicorp has fewer side effects than Caverject and 80% of people who didn't respond to Caverject responded to

Invicorp in the trials. Invicorp is similar to Caverject in that it has to be injected into the base of the penis a few minutes before making love.

Chris: Caverject does not seem to work with me in my stage of MS now. As far as you know, is that a predictable situation? Will vacuum method offer results usually in such cases?

Nolly - nurse specialist: Vacuum pumps are about 90% successful in all conditions. It is important to realise however that they take practice and that you can't just take one home and off you go. It takes time to learn how to use it and establish which size ring will maintain the erection.

Chris: I'm not sure if Invicorp is available here where I am (outside the UK), and you say it's not launched in UK yet. How then might one get hold of it?

Nolly - nurse specialist: Invicorp will be launched in the UK later in the year. I had expected it June but it has been delayed. I am assured it will be available later on in 2007. If you go to the Ardana website [ardana.co.uk] and look at products in the pipeline, it will give you information on Invicorp. It is available on named patient basis but would have to come from a specialist centre until the launch, when it will be widely available.

Geoff: OK, thanks. Since MS and the break up of my marriage, I've tended to assume that my sexual days were over. It's good to see there are things around that can help.

Sandy: Can MS patients take something to increase their libido? If so, what should I take?

Nicki - MS lecturer practitioner: Sandy, there is a drug that I have heard that has just been licensed in the UK for menopausal women who have problems with libido. It's available on prescription if you are menopausal. It's a patch and is called Intrinsa. If you are not menopausal then I am afraid at the moment there is no single drug that can be given to you. They have done research into drugs that work for men such as Viagra on women with MS but they don't work well enough I am afraid

Nolly - nurse specialist: Some consultants will still give testosterone implants to post menopausal women. But there can be side effects including facial hair growth.

Simon - MS Trust: Intrinsa is a skin patch that constantly releases small amounts of testosterone which is absorbed through the skin into the bloodstream. Although associated with men, testosterone is produced naturally by both men and women. Decrease in testosterone in women has been associated with low sexual desire, reduced sexual thoughts and reduced sexual arousal.

In clinical trials, over six months, Intrinsa produced an improvement in sexual desire, and satisfying sexual activity compared with placebo. However, the clinical relevance of these results has been questioned as the effect was small and many patients did not respond to treatment. women over 60 or those taking certain types of oestrogen (oral conjugated equine oestrogens) showed least response.

Sandy: Do other MS sufferers feel the same way as me - with continence problems and using a continence pad, I don't feel very sexy and my husband thinks of me as my carer, not my lover

Nolly - nurse specialist: Hi Sandy. Wearing a pad all the time will not make you feel sexy. You don't say what size of pad you need. There are now some really pretty sexy knickers available that have a pad in them which are re-usable they look like normal knickers and can be washed up to 100 times.

Jane: The frustration I have is a lack of sensitivity in the key areas - plenty of libido, but numb bits that make orgasm all but impossible. Anything that can restore feeling or get thru to the dulled nerve endings?

Sandy: I also have problems with getting any satisfaction during sexual intercourse, I cannot achieve orgasm and have lost interest in initiating sex. My question is - As myelin helps to conduct messages along nerve fibres, is it possible that messages do not get through to the genitalia strongly enough in people with MS to make a good satisfactory orgasmic sex life? This obviously affects my husband as well. We are very close and want to go back to an active mutually satisfactory sex life. If lack of strong messages getting through is the case, have you any suggestions of how to improve things?

Paul: My libido is stronger than it has ever been - but my sensitivity is some way down to its lowest ever! As Sandy has commented, I guess this is down to myelin damage. Is there anything I can do to help with the sensitivity? I end up being like a dog on heat most of the time!

Nicki - MS lecturer practitioner: That's a really good question. Sandy is right, one of the reasons people have orgasmic problems can be due to loss of myelin in the spinal area. Often people will say they have numbness in their genital area and that affects their ability to orgasm. If you can't feel the stimulation it can be hard to orgasm.

Mary: So what can I do to get those BIG O's back?

Nicki - MS lecturer practitioner: Some say that they have an orgasmic response but it is not the same as they used to experience. Then I go back to getting people to work with their orgasm, as they feel it starting they may find fantasising can be really helpful to improve the orgasmic response. Or they may find extra stimulation on one of their other erogenous zones can help.

Both men and women find it easier to orgasm with oral sex. For some people this is not an activity they have used before, but it is certainly one that can improve orgasm. If you haven't tried it and are rather nervous, then some people find kissing and licking through a silk scarf or silk underwear can be helpful.

But oral sex is not for everyone and it's important you only do things that you are comfortable with.

Jane: I can vouch for the oral sex suggestion Nicki (getting graphic now...). I'm not sure why, but if my partner sucks on my clitoris then I can actually feel it, which is more can be said if he just uses his hand. I wondered if there are any sex toys that could help?

Nicki - MS lecturer practitioner: Jane, we are getting graphic aren't we, but still all safe! You may want your partner to suck a peppermint or one of those

minty sheets before he gives you oral sex. That may help too. Just a thought. You may want to look at the websites listed at the end of the session. There are all sorts of sex tools on there.

Nolly - nurse specialist: I can vouch for the use of spearmint thins

Anne: The comment about oral sex is interesting. It really works for me, but my boyfriend isn't at all keen (well, that way round at least!). What works best for him, is less good for me :-)

Nicki - MS lecturer practitioner: It's important to consider what sexes it up for you. These are some ideas that people have said to me, you may know most of them:

- fantasy
- vigorous use of a vibrator - there are the traditional ones like the 'rampant rabbit' or there are ones that don't penetrate but work on the outside of your genitalia. These are a bit more pricey, but maybe worth a try. There is a website called emotional bliss and I know they have them on there
- lots of lubrication is really important - warmed up versions of lubricant are the best. They must be water based. They are easily available in a chemist. They are always situated by the condoms in places like Boots, etc
- oral sex can help
- you may want to consider body mapping as I discussed earlier
- you may need to talk to a health care professional as drugs you may be on for your MS can affect orgasm too especially anti depressants

Chris: I'm glad the subject of sex toys came up. I've never heard of rampant rabbits or the differences between penetrative and other ones. I have heard about the warm lubricant but not how to get it. Are there reliable sites/other sources of info/products for a neophyte like me to find ways to please my female partner?

Nicki - MS lecturer practitioner: The MS Trust and myself have written a book aimed at women with MS who have sexual issues. Within that book are all sorts of suggestions and 'safe' websites etc. It will be published in late May. You will be able to get one from the MS Trust office, keep an eye on their website and they will announce it

There's a list of websites at the end of the session. You will find all sorts of things that can be useful

Simon - MS Trust: Yes, the book Sexuality & MS: a guide for women will be published soon. You can find a little more info at www.mstrust.org.uk/sexuality and in the next issue of the Open Door newsletter (out on 9 May).

Nolly - nurse specialist: Durex has now got some warming gels available, which can be purchased from most supermarkets. KY gel is not designed for sexual activity.

Marjorie: What are warmed up versions of a lubricant - are they safe for females? I do use a hot shower or bidet jet to stimulate my clitoris if on my own. Would the lubricant have the same effect?

Nicki - MS lecturer practitioner: Lubricants are obviously important in making sex more comfortable, whether this is with a partner or on your own. They work best if they not only lubricate the area but also warm it up too. If the genital area

is warm, blood flow is better and this increases your chance of orgasm and/or increasing sensation.

The lubricant must be water based. These are certainly safe for women but the lubricant will not give you an increased sensation like the shower head does.

Some find an electric toothbrush can help stimulate the clitoris too! No jokes please (well you can if you want!!)

Nolly - nurse specialist: If you use a toothbrush don't forget the spearmint toothpaste!

Marjorie: I've just had a suprapubic catheter fitted and I feel rather self conscious about trying to have sex with it in place. How do others cope? I do not have a permanent partner which makes things harder, although my ex husband still likes to try to have sex with me. It is difficult because of severe spasticity virtually 'gluing' my legs together. Are my days of blissful sex at an end? I'm only 55 and can't imagine future with a dead useless zone there too.

Nicki - MS lecturer practitioner: Lack of sensation in your genital area is difficult. One of my colleagues recommends her patients to use a minty gel such as toothpaste in the genital area. You may think it sounds crazy, but it causes a tingle.

One lady I see who has a suprapubic catheter too has brought a few pairs of crutchless (or is it crotchless) pants, which she puts on prior to having sex. They hide the catheter but still allow access to her genital area

Marjorie: Good idea. Thank you Nicki

Nicki - MS lecturer practitioner: The clamping of the legs is a problem isn't it! One lady finds if she lies on her back and grasps her knees, pulling them towards her, this allows her to have penetrative sex. Another finds lying on her side the best whilst her male partner enters her from behind. Another lies over the back of the sofa or a chair

Lying on your back though with your legs outstretched does increase spasticity. It's best to roll a towel up and place it in the centre of your back and perhaps another under your knees

Nos: Interesting stuff coming out of the chatroom. It's an education just to read the many complex issues of a personal nature.

Could the professionals discuss the benefits of teaching sessions to aid other professionals in dealing with some of these personal issues.

Secondly, I'd like to point out that being a man in a professional capacity, I feel poses a greater problem for discussing sexual issues of a personal nature than a women. Please don't come back with the argument, that the same applies to women. Believe me as a man working in a female dominated profession, if any complaints or concerns are raised, the man is guilty until proved innocent. Sad I know, but like I said female dominated.

I'm tempted to stay well clear and seek an alternative compromise.

Simon - MS Trust: What is your professional capacity? Do you see people with sexual problems on a regular basis, or is it a more occasional contact?

Nos: I see patients on a regular basis. Sexual issues, relationships, family dynamics, functional abilities, erectile dysfunction are all topics which may be discussed during the consultation. I would say that topics of a personal nature were discussed on an occasional basis.

Nicki - MS lecturer practitioner: I find people with sexual problems find it easier to talk to a stranger or friendly professional than with their partner, so gender doesn't always come into it. As you are totally aware, if we give 'permission' for sexual issues to be discussed then the individual has a choice to respond or not. You know the permission is the key.

But lots of the male consultants I work with are not keen to ask women about their sexual issues - they worry about being misinterpreted and so on! It is an issue.

One of the unions of nursing say that if we are to ask patients about sexual issues, it should be listed as a role within our job description

Not sure if any of this helps?

Nos: Cheers Nicki. I will check my job description right away. Somehow, I doubt that it will be in but maybe it should. The same goes for my colleagues who are female.

Having said that I feel that, in 2007, we are only just starting to discuss openly these sensitive topics. No problem in a closed room with a patient and their partner. The problem arises when one needs to discuss coping strategies with colleagues. I suspect there are certain health care professionals in higher management that would not approve of discussions or debates about sexual issues. I have had various comments made by fellow professionals who think that it is wholly inappropriate. I have asked one of my female staff to become acquainted with all the various aids and adaptations relating to appliances used by some people to improve their sex life. I have also asked that she enquire as to any training that is available by experienced professionals such as you. I'm waiting for the backlash from the Dinosaurs.

We fondling in the dark trying to engage some patients in conversation about their relationship difficulties. Many staff use their own personal experience as a knowledge base to deal with some of the issues. Not a good idea.

If you could advise on how to get a professional health care professional up to a competent level of dealing with sexual issues I would appreciate it.

Bye for now. Got patients to see.

Nolly - nurse specialist: There is some basic training available for health care professionals called NEED. If you contact your local Pfizer rep they can give you the details.

Jane: Why do people with MS have to go to the loo about three times when you are having sex? Is there anything I can take? My sex drive is still high, but I don't enjoy it as much now, as it takes me ages to have an orgasm, due to lack of feeling down there. Have you any ideas?

Nolly - nurse specialist: Needing a pee is a common problem. Have you had your bladder scanned to check it is actually emptying and is this the only time you need to pee in a hurry?

Jill: I've had a similar thing to Jane. Sometimes it's not actually the need to go to the loo, but the thought that the urge to pee might come on quickly, and this distracts me during sex

Nolly - nurse specialist: The sensation of needing a pee or actually experiencing urine loss during intercourse is sometimes due to unstable contractions of the bladder. Experimentation with positions can sometimes help as can the use of some medications.

Nicki - MS lecturer practitioner: I was looking at some websites recently and believe it or not you can buy specially designed towels that can be placed on the bed for when you're having sex and may wee a bit as well! It's obviously a common problem in the general population. I had a look at the towels, but reckon they were fairly standard although were racy colours like red or black. Perhaps buying your self a red towel that you can place on the bed/sofa wherever, may increase your confidence and can make the bed more sexy looking! Just an idea.

Jane: When my little girl got to the potty training stage I used Pampers disposable bed mats. They go under the bottom sheet and have a plastic backing to stop leaks soaking the mattress. Of course, she got potty trained, and I had a pack of bed mats unused - so now they go on my bed! Discreet but they give me peace of mind ;o)

Nolly - nurse specialist: You can also buy reusable sheets that do the same thing. They lock away the urine and can then be put in the washing machine. This is hygienic as, unless you have an infection, urine is actually a sterile fluid

Jill: The towel and Pampers sound like good ideas for the practical side of the problem, but it is still a big psychological problem for me

Jane: I understand exactly what you mean, Jill. I don't know if there is any solution to this apart from limiting drinks for an hour or so before sex or using Desmopressin spray (usually for bed-wetting), which I sometimes do.

Nolly - nurse specialist: for bladder problems desmopressin can be useful, as can drugs designed to stop bladder spasm, but it is important that it is established that the bladder does in fact empty and is not compounding the problem

Nicki - MS lecturer practitioner: I can imagine that the psychological impact of your problems is huge! I must admit though I know of a couple who wee on each other as part of their foreplay! Not for everyone I know!

Jill: Ummm... it takes all sorts. I think the towels sound like a better alternative for me :-)

Nolly - nurse specialist: I know of couples that make love in the shower so that urine loss is not an issue

Jane: Hmm, I've heard of the 'golden shower' idea, does nothing for me personally though! I think the best thing is not to take sex too seriously, keep communication open and I TRY to not let it bother me. My boyfriend is very supportive and reassures me all the time that it's just not an issue for him, which makes a helluva difference...

Nolly - nurse specialist: Jane you have identified the most important element and hardest to achieve communication, well done.

Jim: That's very true about talking. My wife and I always thought we had a good sex life. Oddly, when MS started to cause things not to work properly and we started to have to find other ways of doing things, in some ways it got better. The equipment doesn't really do what it should - which is frustrating, but our level of intimacy has been heightened by talking about what we both like and finding other ways to please each other.

Nicki - MS lecturer practitioner: You are so right! I have lots of people see me with issues in their sex life but they seem so frightened to talk to one another about it. I had one chap who was so scared of not being able to please his wife anymore that he just avoided sex all the time. She ended up thinking that he had gone off her sexually, which wasn't the case at all. Once they started talking so many things have changed for the better. Life isn't perfect for them, but it's so much better than it was

Vi: I'm scared when we make love because I'm conscious that I'm going to wee myself and so can't let go completely. Reading through the posts, though, I see that this is a very common problem. I'd love to be able to thoroughly enjoy myself, as I used to. Is it because the vagina lies very close to the bladder?

Jane: Thanks for this opportunity to chat about a sensitive subject. I've already told the boyfriend about the toothpaste/mints idea. As always, he's up for trying anything once! Bye :o)

Chris: Thanks for all that info. On the questions above and my own - if an erection can be achieved one way or another, is it still unrealistic/counterproductive for the man to expect sufficient arousal/sensation to reach ejaculation? The sensation in my penis is reduced to the extent that ejaculating too difficult/troublesome.

I feel turned off from sex for a combination of factors - firstly, that I don't have an erection, so need to focus on pleasing my partner other ways, which she is ok with, but what about my own pleasure, I feel, so it becomes a job of work.

Nicki - MS lecturer practitioner: Chris, this all sounds very difficult! I suppose once couples have been in a relationship for a while it is hard work to maintain it, but for you it is more problematic. Is there anything that has been said today that has helped?

Chris: Thanks Nicki. I'm sure it is mostly about communication between me and my partner. I guess I basically feel bad about my body now, and so about myself.

Nicki - MS lecturer practitioner: Perhaps you and your partner could write down five things about each other that you really admire/like etc and then show

them each other. I think you will be amazed at what she says and it can help you feel so much better about yourself! Is there any other way you can think of to improve your self esteem?

Chris: Thank you Nicki. It's not rocket science, and I guess there is no technical or pharmaceutical magic bullet. It's tempting to bury the issue.

Nicki - MS lecturer practitioner: That's an important place to be isn't it? You are ready to move on. There is no magic drug, but there are lots of strategies that may help you and will certainly be fun trying out anyway! Be adventurous, be confident. Your partner obviously thinks you're great

Chris: Just by the way, when trying to have another child (using the technical means and expertise available) a few years ago - it turned out that my sperm count/motility were very low. Not scientific data, but I cannot help but wonder if it is related to either progression of MS or taking the Beta Interferon for 10 years.

Nicki - MS lecturer practitioner: MS itself does not directly affect fertility, but obviously if ejaculation is an issue then fertility is affected. There was some thoughts initially that the interferons might affect motility of sperm but over the last few months it has been found that this may not be as much an issue as originally thought.

Molly: After about a year of total numbness, I find my husband can bring me to orgasm with clitoral stimulation. But the minute it starts, I go into terrible painful spasms in my legs and have to stop even after taking baclofen. Oh my god, it is so frustrating

Nicki - MS lecturer practitioner: That sounds really frustrating! I am sorry but I am not sure what to say here. The only thing I can think of is again about lying on your back. If you are perhaps lying on your side is worth a try when you are orgasming to see if this helps?

Chris (a different one): As a male, is the fact that I use intermittent self catheterisation (ISC) likely to have any effect on either erection or ejaculation? I don't know if it's a coincidence, but since about the time I started ISC, I have produced very little ejaculate, and have a strange, slightly unpleasant feeling when ejaculating, as if the ejaculate is going the wrong way, into my bladder. I understand this is what happens with prostate problems and wonder if the catheter has damaged my prostate. I am 55 years old.

Nolly - nurse specialist: ISC does not effect your ability to obtain an erection or ejaculate. Problems with the prostate gland can cause problems with erections but the problems with ejaculation may be MS related.

Chris (a different one): Can MS reduce the amount of ejaculate?

Nolly - nurse specialist: As you get older the amount of ejaculate reduces and the consistency changes. This is a normal part of the ageing process.

Chris (a different one): I have another question relating to medication, and its effect. I take baclofen for muscle spasms, Detrusitol XL for my bladder, and Pregabalin for the pain. I find I have loss of sensation, and this does make me less keen, so I get into a bit of a vicious circle. I have tried to decrease the medication, but find I can't do without it for long - although my performance and sensation did seem to improve when I did this. I just wondered if it is the side effect of what are, after all, muscle relaxant medications, or the MS, or both. Is there anything that I can do about it?

Nolly - nurse specialist: Which medication did you come off of?

Chris (a different one): It's a case of trying to find the right balance between the three. Do any of these drugs affect performance, or is it a combined effect?

Nolly - nurse specialist: Detrusitol can have an effect on erectile capability but is not a common side effect.

Terry: When I have sex with my partner I don't seem to be able to ejaculate. Why is this as I can ejaculate when masturbating? I have to take tadalafil tablets to get an erection.

Nicki - MS lecturer practitioner: Hi Terry, I hope you don't mind me asking, but do you enjoy masturbating more than having sex with your partner?

Terry: Not really. My partner doesn't seem to want sex much since we got married. She only wants to after she has had a drink. When I masturbate I'm thinking of her.

Nicki - MS lecturer practitioner: When you masturbate you know, of course, what you need to do to achieve orgasm, but perhaps you don't experience the same pleasure when having penetrative sex. The good thing is that you can ejaculate so perhaps it's about changing your sexual approach with your partner. Do you think you have lost your sexual confidence when having sex with your wife? Have you and her been able to discuss her lack of sexual interest?

Terry: Sort of. She just goes off on one saying I always want sex, which isn't the case. Would it help if I just stop masturbating?

Nicki - MS lecturer practitioner: It's interesting what you say, Terry. Do you think you and your wife still have intimate times together that don't involve sex? I suppose I am thinking, does she think that every time you kiss, cuddle and so on, that this will lead to sex?

Often couples have let their intimate relationship drift a little and do less enjoyable (non sexual) things together. I see couples who don't go out together anymore or even sit and have a meal together anymore. They only speak about MS or about the kids and have forgotten that they must have fancied each other like mad at some stage and enjoyed just being together.

Terry: Yes we do kiss and cuddle a lot, but I don't think about having sex. It's like I said before, my wife only wants sex after she has had a drink, or should I say a lot of drink, which does put me off quite a lot.

Nicki - MS lecturer practitioner: Have you asked her why she doesn't want sex with you in between times? Perhaps she's worried about something? Perhaps she feels unsexy and has lost her self confidence?

Have you tried wooing her lately? Take her out for a meal or organise a takeaway? Candlelight? Put a post-it note with something loving on so when she opens a cupboard (for example) she will see it? Sitting watching a movie together? I don't mean to sound patronising

Terry: No I know what you mean. I'm always telling her she looks beautiful and good looking. Funny you should say about leaving notes. I wrote her one for her to see this morning before she went to work. I've done that quite a few times and sometimes she would write one back. After we have had sex she tends to say she is sore as I'm big down below. Sorry, that sounds bad.

Nicki - MS lecturer practitioner: Just because you are large this shouldn't make her sore unless she is dry vaginally. don't you buy some vaginal lubricant for your wife? You can easily get products in the chemist. Durex produce a product called Sensilube, but if you look by the condoms, the vaginal lubricants are usually stored there too. Use lots of it on your penis and ask your wife to apply it to her genital area. Does she find it painful when you penetrate her or is it just sore afterwards? Why

Terry: While having sex as far as know - we don't talk about it really. I will go to the chemist tomorrow. Thank you.

Claire: I have read your questions and comments with interest. Both myself and my partner have MS (it certainly solves the 'oh I'm sorry it the MS' issues) and I have great problems with lack of sensation.

I don't get any pleasure from oral sex nor can I use hand stimulation (my partners or mine) and I don't get much from sex either. The only way I can orgasm is from a select few very powerful vibrators. We have tried the peppermint and that just burnt! Is there anything else that will bring me back to life?

Nolly - nurse specialist: Have you tried body mapping to see if you have areas of heightened pleasure?

Claire: No, we haven't tried body mapping, but we are slowly discovering areas that are more sensitive. We will have to try it.

Nicki - MS lecturer practitioner: The lack of sensation is obviously the main issue here. The fact your body is not actually appreciating feelings of sexual pleasure means that your brain is not able to respond appropriately and you will not easily be able to orgasm.

For you it is concentrating on your brain (the most powerful sexual organ a woman has). Some women can orgasm by thought alone, although not many! I have already listed some games and other strategies that make some feel more aroused, are any of these any good to you?

Thomas: To some extent the previous chat has answered some of this but... I'm a 38 year old male. I was diagnosed with relapse/remitting MS in 2003. It's a very mild case and I'm still in remission since my last relapse in late 2001. I'm on Copaxone and have been since mid 2003. I don't currently have (and haven't previously had) any noticeable sexual dysfunction. I'm not sure if erectile dysfunction or problems with reaching orgasm can be symptoms of MS. Are they? What other sexual issues are there for male MS patients?

Nolly - nurse specialist: Most investigations have found that sexual dysfunction is not related to the duration of the MS or the level of mobility, but is clearly associated with bladder and or bowel dysfunction.

Simon – MS Trust: Vicki Gutteridge and Ruth Hallam-Jones have now joined the chatroom to answer your questions. Thanks to Nicki and Nolly for all their input this morning.

Nolly - nurse specialist: Thank you to all for allowing me to take part in what has been an informative experience.

Nicki - MS lecturer practitioner: Thank you all for your questions this morning. Have lots of fun experimenting with some of the ideas we suggested!!

Rose: I am currently going through the diagnostic process but my neurologist has discussed MS as a distinct possibility. I am 48 and married to a wonderful man but have (like so many it would seem!) experienced diminished libido over some years. At the moment I am just recovering from a numb bum and bits episode (along with foot drop and other things). Something I have noticed over the last couple of years is that if and when I begin to get aroused sexually (due to my husband's patience and persistence), I experience acute discomfort travelling up the posterior wall of the vagina. This appears to occur before natural lubrication and PRE penetration. It seems only to occur at arousal. Is there an explanation for this and anything I can do in the future?

Ruth - psychosexual therapist: You do need to discuss the discomfort with your doctor, but both men and women can get discomfort during arousal if the vascular system is not as good as it was - like cramp. Have you heard of Eros, a pump to increase vascularity for women?

Vicki - MS specialist nurse: There may also be the potential for your sensory nerves to fire off or even 'cross fire', which can produce odd, uncomfortable and sometimes painful sensations to certain stimuli (it is benign but not very nice). As Ruth has said, it needs to be discussed with your doctor or specialist nurse

Rose: Thank you both. Your discussions have really helped me and my husband to put things into perspective at this time. I have bladder, bowel and leg problems so can now associate the sexual difficulties with this. I will feel more confident in discussing this with my doctor now.

Vicki - MS specialist nurse: I am very interested in the Eros. Could you explain a little more to us?

Ruth - psychosexual therapist: Eros is a new device for women and can be very helpful for women with MS. Beecourse, the English agents for it, are trying to get it prescribable for women on the NHS. However at present it has to be bought privately (see the Beecourse website at the end of the session). It acts like a pump for women and can increase sensation, lubrication, arousal and orgasmic ability. Useful also for women with diabetes who have sexual problems.

Vicki - MS specialist nurse: Thanks, sounds very interesting. I know of several people with MS who might like to give it a try.

Karen: Since my latest episode in December, the vertigo I experienced at that time has not calmed down, making sitting, lying down etc difficult. I would like sex with my husband, and as the days go by and nothing is changing I become more frustrated with the whole situation. I am not currently taking medication, other than anti-depressants. Can you suggest anything that may help the dizziness and vertigo!

Vicki - MS specialist nurse: There is a variety of medications that will help with dizziness, and a range of exercises that help to 'retrain' the brain in balance. In fact some of them involve lying side to side on the bed. You could make it a joint venture with your husband helping you. This problem can take sometime to settle.

Ronnie: I've had a weak right leg for five months and have lost all sexual function. Is it the weakness that's causing it? I've had relapsing/remitting MS for 15 years.

Vicki - MS specialist nurse: When someone with MS has problems with their legs, bladder or bowel they will often have problems with sexual function. Each relapse can take a different length of time to resolve and winter is the more likely time to relapse. So it could relate to this relapse. But you also need to ensure you are screened for any urinary infection that you are NOT showing symptoms of. And what about your anxiety levels? Any other stresses and worries which may also affect sexual function?

Ronnie: You're right about winter. I always seem to have them at this time of the year. Why is that? Morning erections have stopped altogether but a few have returned in the past week, so maybe I'm coming out of relapse. But the leg is still feeling a bit weak. So it probably is the attack causing it.

Vicki - MS specialist nurse: We are not sure why relapse happens more frequently in winter. And another thing is the widespread phenomena of SAD (seasonal affective disorder), which affects people from about Oct to April. It maybe that you are emerging from a number of things that have affected your sexual function. It is still worth discussing with your doctor, but I think that if things are slowly beginning to pick up I would be optimistic that you are on the upward trend.

Ronnie: Thanks so much for your opinion and that you think it probably is relapse related. If it had gone on any longer I would have mentioned it to my neurologist and not my doctor. I've known him for too long.

Irene: I am female and 48. My illness has caused great stress for me and my husband. Severe pain put a stop to penetrative sex about ten years ago - both my husband frightened he would cause me pain and me not enjoying it because of pain. Pain medication doesn't work.

Our relationship does a great dip every time I have problems with my health and I end up feeling very lonely and sad, even consider suicide. I feel so alienated and alone when just a smile or a cuddle would pick me up. I miss my loving caring husband but as soon as there is a little bit of stress he is angry and awkward with me.

We have even talked about separation because his family give him no emotional support, they do not believe anything is wrong with me and put him under pressure to 'sort me out'.

I am sorry to give you such a depressing picture but would be very grateful for any advice. I exhaust very easily, so things like showering and dressing nicely or making a meal I cannot manage on my own. Thankfully after respite care I may have some carers who can take the load off my husband.

Please I am after any advice you can give me

Rose: Irene, I am not one of the specialists but a mental health nurse awaiting confirmation of a diagnosis of MS. My heart goes out to you but please, please talk to someone professional about your suicidal thoughts. You would really benefit from specialist input. Are you currently prescribed anti-depressants or have access to counselling?

Ruth - psychosexual therapist: Irene, it is hard for both of you to have lost what you had. Hard also to move from the patient / nurse role to partners again - but have you asked your doctor for some couple counselling. It could be so helpful to have experienced support to see if you can improve the relationship and alter some of the current stresses.

Vicki - MS specialist nurse: As Ruth has said, it's a very difficult time for you both and one that makes you feel very alone I am sure.

Firstly allow yourself the right to be sad, and to free both of you from the burdens of guilt. Your husband may feel a responsibility to make it all better. He may feel very guilty because he can't and doesn't have MS, you because you do have it and it affects his life. All these severe thoughts and anxieties will affect both the severity of your symptoms, the intensity of your fatigue and the quality of your daily life. It hurts that much sometimes doesn't it? As Ruth has said the very first step is to talk to someone outside of the immediate situation. I am recommending this as both a nurse specialist and a counsellor.

J: I can understand Irene's situation. I have a partner who struggles to cope with the fact that I am quite ill at times. This combines with a rather poor self image and much reduced sex drive, which tends to build into a downward spiral

Vicki - MS specialist nurse: It is a spiral, you are absolutely right. What it needs sometimes is someone or something to change the direction of the spiral. This is where an outside catalyst can help. Poor self esteem, low self image and all the worry of being a burden affects relationships, especially at stressful times

like illness. This in turn, affects sexual relationships and lovemaking and that affects self esteem and so it goes on.

One helpful thing is to create some new 'ground rules' for when you are very symptomatic or relapsing. This will help stop some of the 'muddle' about what is right to do for what occasion. Allow yourself to rest and recuperate properly, and to put on hold some of the mainstream things until you are stronger. Then promise both of yourselves a special event when feeling better.

Start to think about some feelgood activities that your body will enjoy that are not immediately related to the sexual act, such as a massage (if you like them), some reflexology, a beauty treatment. Build your self esteem slowly, and then list all the wonderful things about you and those you would like to change, and are able to. Some we cant, and have to work at being comfortable with them.

It would be worth you talking to your specialist nurse or a counsellor if it really hard for you to manage

J: You read about pampering yourself or trying to lift yourself out of the spiral - but it is very difficult to take the first step when you feel that the sexy young thing you might have been has become a limping, fatigued, dowdy lump. I realise it's going to be a state of mind thing but that first step seems so difficult.

Vicki - MS specialist nurse: I think that a woman who is as caring and loving enough to want to be her best for her husband, as you clearly do, is a very beautiful woman indeed. It is now the practical steps that we need to get under way, isn't it? Time to match up on the outside what is so clearly on the inside. Someone very special who loves her man. Lucky him

Simon - MS Trust: A specialist health professional (not MS) sent the following question in in advance. I wonder if Ruth and Vicki have opinions on this.

"Do the panel feel that it was essential that a MS nurse be employed wherever possible to help deal with the needs of people with MS. Not least the sexual needs but the educational needs of professionals attempting to care for patients with this condition.

Is it appropriate that some PCTs choose not to employ Specialist MS Nurses but rely on the skills of existing multidisciplinary team members or specialist nurses from other areas to attempt to deal with the specific needs of patients with MS."

Ruth - psychosexual therapist: Vicki, I am presuming that most nurse specialists would be happy at least initially to join a couple to look at coping together in these difficult times

Vicki - MS specialist nurse: MS is a condition of young people and it is essential that a specialist nurse be available to discuss sexual issues with the person with MS, or as Ruth says, with the partner as well. Another critical point is that sexual dysfunction will go hand in hand with other complex, specifically MS related problems. This is unlikely to be picked up or identified with a generalist. The training given to MS specialists equips them to give the initial assessment and treatment interventions, and to know when it is important to refer on

Ruth - psychosexual therapist: However don't forget we are also people who can have other issues, problems and illnesses. The sexual problems or the relationship issues might have come anyway for different reasons. We always

need to check with someone who can ensure we have a thorough physical, psychological and relational assessment

Vicki - MS specialist nurse: Ruth is absolutely right. It is easy to hang everything on the hook of MS when it may be a wide range of factors. An important thing to remember.

Mrs CS: Can I ask the group if there is likely to be an MS Nurse in Doncaster in the near future? I think that they could be an additional asset when dealing with sexual issues and problems.

Vicki - MS specialist nurse: I am not sure what the situation is in Doncaster re nurses and we can get back to you on that one I am sure. You are right in that it is a very useful asset in discussing issues like sexual function and relationships. The GP is very experienced in these problems but not often MS specifically.

Simon - MS Trust: It looks as if Doncaster is covered by the Sheffield MS nurses. People in Doncaster need to be under a Sheffield neurologist.

Teresa: There is no nurse in Doncaster dealing specifically with MS. There are some nurses but they are not specifically MS. I get all my advise from Sheffield.

Vicki - MS specialist nurse: Thank you for that. Maybe we can feel some lobbying coming on! They are a great crew at Sheffield.

Ruth - psychosexual therapist: The Porterbrook Clinic, a clinic in Sheffield specialising in helping people with all kinds of sexual and relationship problems, has a contract to take referrals from Doncaster.

Janet: I know there is a Neurologist in Doncaster. Why do I have to go to Sheffield? I agree the Sheffield nurses are a great bunch.

Brenda: I need to speak to a nurse about my husband's sexual problems. My GP was not helpful. How do I contact a nurse in Sheffield?

Vicki - MS specialist nurse: Your husband needs to be under the care of one of the neurologists based there and also check to see if you could have a referral to the clinic mentioned by Ruth - the Porterbrook at Sheffield. Alternatively you could ask your GP to refer you both to an MS nurse at Sheffield if he/she is able to fund this.

Simon - MS Trust: Brenda, sexual problems can also be managed by a urology team. Nolly, who was online earlier in the day, is a urology nurse specialist. It may be worth asking your husband's GP to refer him to the urology department at Doncaster Royal Infirmary. If he wants to see an MS nurse and is not yet seen by a neurologist at Sheffield, he'll also need the GP to refer him.

Rachel: Ruth, you're listed as a psychosexual therapist. I've not come across one of those before, could you explain what it means? Thanks

Ruth - psychosexual therapist: Sure Rachel, it means I trained as a psychotherapist to work specifically with sexual and relationship issues and sexual medicine treatments.

Mary-Jane: I've read the discussion so far and agree with the really helpful advice offered so far. I'd like to add that the Sh website is a very useful resource. This is the site for a sexual health shop especially for women. The shop itself is in London and is a very comfortable place to be. Men can only enter if accompanied by a woman. It isn't at all seedy and the staff are helpful but not intrusive. Well worth a visit - to the website or the shop.

Vicki - MS specialist nurse: That is very helpful Mary-Jane. Thank you. Some other useful (and safe) websites are listed at the end of the session

Simon - MS Trust: As we're listing useful resources, can I mention that the MS Trust will shortly be publishing a book called Sexuality & MS: a guide for women. Find out more at www.mstrust.org.uk/sexuality

Suze: I feel bereaved of my sexuality. I haven't had an orgasm in years, can hardly remember the last time I was even aroused. My partner's very tolerant and I still enjoy the intimacy of sex with him. It's comforting to see that so many people with MS have a similar problem. My GP prescribed Premarin vaginal cream (HRT). I've just started using it, so no results yet. Any comments?

Vicki - MS specialist nurse: That is such a powerful description "bereaved of my sexuality". What would normally turn you on? Can you give yourself an orgasm at all?

Suze: I used to be able give myself an orgasm by masturbating with an improvised dildo (roll-on deodorant bottle - they're such an inviting shape!), but for a year or so I haven't even managed with that. I can't even turn myself on - so depressing!

Ruth - psychosexual therapist: We all may need more help to increase sensation as nerves get less sensitive or older or are damaged in trauma, illness or surgery. Vibrators can help if they are powerful enough and it is often useful if they have a variety of pressure levels and speeds

Vicki - MS specialist nurse: Sex problems can be thought of as what we would call primary, secondary or tertiary problems. This means they are caused either directly by MS lesions (primary), by the symptoms of MS that can interfere with sexual function such as pain, fatigue, depression etc (secondary), or the consequences of living with MS, the impact of it on quality of life such as low self esteem, loneliness, change of role (tertiary).

How to tackle the issues depends on the source of the problem and also, as Ruth says, whether it is something outside of MS all together.

Start by making a list of all the things you think may be affecting you. Then it can help in working out a programme. Again, talk to someone you can trust such as your MS nurse or GP. If you are lucky you may have a sex therapist in your locality.

Sorting out a problem with expert help can make such a difference in success or failure.

It may be a matter of trying some stimulus not tried before, such as sex movies, or sorting out a symptom that is troublesome, or an issue with self esteem

Suze: Thanks for your comments. I'll try to list all the things that might be affecting me - there are lots - and show it to my counsellor. I just discovered she

specialises in sex therapy. I'm post-menopausal but optimistic of finding a way forward for my latent (??) libido.

Marilyn: Two questions to answer if possible:

1. Loss of libido. Is it possible to remedy?
2. I'm now post-menopausal. Is there a more permanent treatment for vaginal dryness, rather than just using KY?

Ruth - psychosexual therapist: There is now new interest in treating women with sexual difficulties but often it is not yet in the NHS. Desire disorder is treatable.

We at restoration-therapy.com have a list of doctors who do work in sexual medicine for private work and you can also ask for an out of area referral to Porterbrook Clinic Sheffield from any NHS setting, but your area will be asked to agree it.

The new hormone treatment is a patch with minimal chance of side effects and is available now for women who are surgically menopausal. You can ask for an appropriate blood test from your GP to help you know if it is a hormonal problem. (see the information in Intrinsic above)

However this disorder has a variety of other causes and needs careful assessment - women are complex and need to be investigated carefully and treated correctly.

Vicki - MS specialist nurse: Thank you for your two important questions.

Loss of libido can result from several problems and can be related to a variety of aspects in your life, including an MS lesion, medication, secondary problems brought about by having to cope with MS and the menopause. You don't say if you have had HRT for your menopausal systems for a specific period of time ?

Marilyn: Might HRT have affected this problem?

Vicki - MS specialist nurse: No it won't be affecting the problem and for many women it is a very useful treatment. Did you see Ruth's message earlier about hormone patches? There are also other lubricants you can use and some of them now incorporate sensory stimulus and create a tingling, which can enhance sex and keep you comfortable in terms of vaginal dryness.

Mary C: I work with Beecourse (see the resources at the end of the session). There are three books that I would recommend The Sex Starved Marriage by Michelle Winner Davis, Rekindling Desire by Barry McCarthy and Perfectly Normal Dr Sandra Pertot

Tuppy: I hope that some of the people who avoid trying to find a partner because of MS will think of joining Outsiders, a club I started which is a self help group for physically and socially disabled people who feel nervous about trying to find a partner. Members gain confidence and are accepted as sexy, disabled people.

I also run the Sex and Disability Helpline and get many calls from people with MS who are worried or frustrated and we have frank conversations about trying new things. The number is 0707 499 3527, 11am-7pm weekdays.

Eric: Me and my girlfriend both have MS. My sex drive is undiminished (with help of Viagra, albeit) but my girlfriend's is nearly non-existent due to loss of feeling. I feel guilty even mentioning sex as I know she probably won't feel like it and I don't want to pressure her as I love her and don't want to lose her. But I also love having sex. We have tried most things. Is there anything we could try to increase the feeling and so increase her sex drive?

Ruth - psychosexual therapist: Oh Eric, please get referred to a couples therapist. There is a LOT OF HELP available for you two.

Vicki - MS specialist nurse: TOTALLY agree with Ruth. There is such a LOT that can be done for both of you. Get referred asap

Eric: I don't feel that seeing a therapist would help, as it's the lack of sensitivity down below that's the problem. I heard once that taking Viagra can make a women feel more sexual. Is there any evidence to back this up?

Kerry: I do have a very high sex drive. Having sex normally isn't have a problem with me and my wife. However, ejaculation makes my leg (affected by MS) spasm, making my leg pull straight hard (unable to bend). I have to lie down for a while before it calms and relaxes. Is there is anything I can do to avoid this?

Vicki - MS specialist nurse: Do you have difficulties with your leg going into a kind of stiffness sometimes anyway and are you on any medication for that? Does the spasm in your leg start as soon as you orgasm? How long does it last for?

Kerry: No, I don't have that problem during sex, only when it happens at the end. I do not have any medication since I was diagnosed with MS ten years ago. But I had started LDN last September. Relaxation came up fully around 30 to 60 minutes after end of sex

Vicki - MS specialist nurse: It may be that a small dose of something like baclofen taken after sex may help, particularly as the spasms can be very uncomfortable can't they? I would recommend a very baby dose such as 5mg and see how you go. Chat to your GP about this. Also change position and ask your wife to do some gentle stretching and bending exercises with you for a few moments. It maybe that orgasm is triggering this response in your leg

Kerry: That's what I thought - an orgasm might be triggering this response in my leg. Thank you for advice. I will deal this with my GP when I visit him.

Molly: I asked this question this morning. I wonder if the afternoon people have any thoughts. After about a year of total numbness, I find my husband can bring me to orgasm with clitoral stimulation but the minute it starts, I go into terrible painful spasms in my legs and have to stop even after taking baclofen.

Vicki - MS specialist nurse: Don't give up on wonderful satisfying sex. Have you tried upping your baclofen dose pre sex? If you do, make sure you go in 5mg steps and discuss it with your GP. It can make you a bit more drowsy, so best if you can be sure of a post coital nap and rest. Also try changing position so that you are with your knees slightly bent and you are lying in a foetal curl. If your husband can stroke you from the rear it may help.

Tuppy: In Outsiders we have been discussing the fact that people who suffer muscle spasms say that orgasms reduce or even stops the spasms. We want to bottle that orgasm substance (oxytocin?) to give it to people so they can enjoy sex without spasms. Might this be a possibility or just a dream?

Vicki - MS specialist nurse: That sounds like an excellent idea!

Kerry: What is oxytocin?

Simon - MS Trust: Oxytocin is a hormone that's released during orgasm (by men and women). Apparently it reduces blood pressure and cortisol levels, increases tolerance to pain, and reduces anxiety.

Tuppy: I quote Kym Byatt:

Before and after sex a woman's body is flooded with at least five different hormones – all of which have health benefits.

Oxytocin - a hormone that promotes the bonding of men and women (it's the same hormone that helps mothers bond with their babies). It is at a peak during orgasm. Oxytocin also has a tranquilizing effect - more so in men. Orgasms heal! An orgasm could be especially beneficial if you are unwell or in pain.

Endorphins - these hormones are secreted into the blood by a gland beneath the brain, and carried through the body, contributing to the feelgood factor often experienced after physical activity. Endorphins can reduce depression, increase self – esteem and act as a natural painkiller.

Testosterone - the male hormone testosterone, though more prevalent in men, also plays an important role in the sex drive of women. Testosterone is produced in small amounts by the ovaries and the adrenal glands in the kidneys. The female sex drive may increase at certain times of her menstrual cycle, when levels of testosterone and the female hormone oestrogen peak.

Oestrogen - production of the female hormone oestrogen increases during sexual activity. Oestrogen reduces the symptoms of PMS, increases fertility and helps to regulate the menstrual cycle.

DHEA - Dehydroepiandrosterone is the main sex hormone. It not only boosts your sex drive; it works towards prolonging your life. Levels of DHEA can be increased through regular exercise and are increased three to five times just before and during orgasm.

Ali: I have had MS for 10 years. Two years ago it converted to the secondary progressive form. The problem is that whenever I have sex, afterwards all the symptoms of my MS become much more acute and I feel I am having a relapse. So I avoid having sex or getting married. I'm 30 and have become very depressed.

Vicki - MS specialist nurse: Does the sexual act bring on some symptoms for you? Do you get anxious or tense about sex at all?

Ali: I do not get anxious, I like having sex. After having sex my existing symptoms get worse, but like when I have a relapse and it lasts for a long time. I do not develop new symptoms.

Vicki - MS specialist nurse: What are the symptoms you experience and how long do they last after having sex?

Ali: Double vision and dimmer vision, numbness in hands and legs below the knees, more weakness in legs. It also affects my balance. They last more than four days, sometimes up to two weeks.

Vicki - MS specialist nurse: I wonder do you get very warm when you have sex? Do you feel that your body temperature goes up? What is it like if you masturbate? Do you still get the symptoms?

Ali: No I do not warm during sexual intercourse. Yes the same thing happens when I masturbate. I feel when I achieve orgasm, it (the climax) stimulates or aggravates all the symptoms.

Vicki - MS specialist nurse: Sometimes the position we have sex in can aggravate some symptoms, particularly in the conventional missionary position. Lying on your side, on all fours in a doggy position, or over the edge of the bed can help. But you describe a set of symptoms that may relate to the chemical changes from sex. These are very good changes as you can see from Tuppy's last text but may have this effect on you. Do you ever have problems with sweating or controlling your temperature?

Ali: No I do not have any problem with that. Unfortunately I have had this problem for many years. My life is ruined by that because nobody can solve this problem for me. I am very unhappy. Thank you anyway.

Vicki - MS specialist nurse: I would very much like you to see your MS nurse about this. I am getting a sense of an unhappiness that may be as influential in this problem as anything else. It could be a chicken and egg situation that needs someone from outside to go through it with you. Take care.

Ali: Where can I get a vibrator or equipment like that to help me get an erection? Can I ask my GP?

Vicki - MS specialist nurse: Vibrators are easy to order on line or at local shops. They vary in power. If you have sensory loss a powerful one will be best. Positioning is also important to get the best effect.

Ruth - psychosexual therapist: And I don't mean to ignore men's new aids for all sexual activity. Have you seen the new chrome rings advertised, not the rubber constriction ones? This is ex-body jewellery that really works well. It aids

gaining and keeping an erection and also makes the sexual medicine drugs work better. It's called a penile-scrotal ring and is available from various sites.

Mary C: Most of the vibrators sold now are non phallic and not threatening. They can be used by men as well as women, especially if the man has decreased sensitivity. If a lubricant (preferably silicone) is used around the glans and the underside of the glans - the frenulum - and a vibrator is applied there most men will be able to feel it and progress to orgasm. He does not have to have an erection for this to happen.

Suze: Are there any vibrators you'd particularly recommend for me- a complete starter in the market? I wouldn't know what to look for online.

Vicki - MS specialist nurse: I would go to the sex shops on line that we recommended earlier and consider a reasonably powerful one as you may have some sensory loss that requires a bit of extra oomph. I would buy a couple if finance permits and see what you like. You may like to add some of the new tingly gels you can get (Superdrug sell them) to enhance this new venture. Have fun with it. Get a good movie (again go to one of the sites recommended) a nice glass of wine and comfy place on the bed and some favourite perfume. Give it a go.

Tuppy: The world's female masturbation expert, Dr Betty Dodson, always swears by the Hitachi Magic Wand as it's sturdy, strong vibrations which can be lowered or raised, mains operated (batteries don't run out) and on a long handle so you don't need to reach down. Betty has also done a brilliant film called the Internal Clitoris to help women understand the full extent of the clitoris underneath the surface. You can see this free on YouTube (see links at the end of the session). Hope you don't mind my suggesting this.

Vicki - MS specialist nurse: Thanks Tuppy. Also think about your hand strength and ability to hold something for some time, so that sounds an excellent idea

Mary C: The Hitachi Magic Wand is not available in the UK anymore as Hitachi will not do a European version. I am a great fan of this product but have sourced an equally good one called the Ideal. The details of my Beecourse website are at the end of the session. We have qualified staff available to help MS patients choose products to suit them and have a new catalogue out too, which details everything in easy to understand language.

Suze: Thanks Vicki. Will get shopping and give it a go - even though my partner may not be too keen on sex aids at first, I'll do it for me.

Fiona: Myself and my partner are 41. We know a lot of people with MS have various problems regarding sexual issues and wondered if our circumstances are different?

We have been together just over a year and both have MS and our sex life just gets better and better. We have sex at least once a day and both find our orgasms have just got better and better and last longer and are much more powerful and wondered if this is usual?

Mary C: I think it is very important that MS patients try to be as sexually active as they can - I have heard of similar cases to you. I really do believe in the more stimulation you give to an area (anywhere) the more sensitive it will become

Allan: It has been mentioned during the day, but I wonder if being unable to maintain an erection is commonplace? If it is I would be interested to know if anyone has suggestions of dealing with this problem. A bit of an embarrassing topic but very important none the less

Mary C: We sell rubber and chrome rings for this. Many men have this problem and anxiety at the wrong moments can cause the erection to fail. What you do is get the correct ring for you, wear it before you get an erection and the ring holds it there during intercourse. This ring is worn close to the body so that the scrotum and the penis are held within the ring

Ruth - psychosexual therapist: Very important - feeling that you may lose it can become as big a worry as the problem. Confidence is such an important part for all of us. The rings might be very useful for this but perhaps the problem is coming too soon?

Tom: I'm a 50 year old trans man (ie born female) with a best friend, partner and now wife, together for 25 years. I have secondary progressive MS - still working, but only just. I use testosterone gel daily and might have thought that would help, but no such luck.

In 2003 I had a new phallus and balls, with an erectile pump so no problems there. Old genitals still intact, behind. I have never enjoyed being penetrated - it upset the equilibrium of who we are - though it was very sexual otherwise.

Now, in the last year, my libido decreased and I have gone from being a once a day man, to a possibly think about it every two weeks or so. And I have lost all capacity to experience orgasm through clitoral stimulation. We might both end up in casualty with repetitive strain injury. We use a warming gel - great for my wife, but does nothing for me - I simply can't feel anything through my clitoris. My vagina still has sexual sensation, but as I said, it makes us both a bit uncomfortable.

I really, really need to get some sensation back in my clitoris so that I can 'cum'. At times I feel suicidal, having turned into a sexual vegetable from being a rampant stud.

Would Viagra help? Are there any external vibrators that look a bit butch? Has anyone any ideas? Fortunately we have always laughed a lot about sex, and still do so, but underneath I am very unhappy about my situation.

Vicki - MS specialist nurse: Welcome Tom. Several issues that are significant here and some questions too. You use the term trans man. Am I right that you have completed all the reassignment?

Firstly I am not expert on gender reassignment although I have a very dear friend who has undergone this.

Secondly I am picking up on issues that might be impacting very much on your sexual satisfaction. Is work pretty bad?

Tom: I have completed all my reassignment - except I did not have the urethra hooked up to the new penis as I was already having a lot of difficulty with peeing due to a lack of sensation there.

Yes, work is desperate really. I am in a very senior management position - finally promoted and we can pay the bills after years of very hard work, and now I am just not coping. Getting things wrong, missing meetings etc.

Vicki - MS specialist nurse: Firstly congratulations on what is obviously a very successful partnership over a long time. Secondly congratulations on promotion to a very senior post. Thirdly congratulations on completing your reassignment and still being active and in the full flow of life. My friend nearly didn't make it with the stress and marginalisation she experienced. So, all in all, you are a pretty special person. Keep that perspective in mind when trying to deal with the problems.

I would suggest that you both retreat a little from the 'demand' of getting full orgasm from sex just for the moment. Let's start by dealing with development of a strategy to get work under better control. If you have an MS nurse you need to see her/him asap to work out your plan of work. You are a valuable asset so a little time out to protect that asset may be required.

Then consider the concept of body mapping to gain sensory pleasure from each other's bodies and just touching, caressing and loving your skin and other areas of the body. Focus on this for the moment whilst sorting out other life issues.

When you are on firmer ground with these things then you can begin to address the issues of clitoral orgasm and how best to gain satisfaction.

It will need sitting down with an expert to go through each stage and setting out alternatives with you both. So no immediate remedies but a staged process that will deal with the tertiary issues, then the secondary and finally clear a space for any primary problems that need to be looked at.

Hope this makes a little sense Tom

Mary C: What a delightfully sensitive answer to Tom, Vicki. I have found Leora Lightwoman's DVD The Beginners Guide to Tantric Sexuality a great help when it comes to helping people with touching, stroking and finding all those little luscious places to touch, caress and kiss. She is gentle and articulate and very moving. I use it on professional workshops for sensate focus programmes.

Tom: Thanks Vicki, that makes sense. I suppose, like everybody, it seems to feel like it all takes so long ... but thinking about it, I am sure you are right. Your previous comment just made me write a list of the different types of work I do and maybe what I could delegate. And I suppose we just have to accept that for the time being, it isn't working - but try and remember that we should be considering how to make it work in the future, by seeking advice and taking our time to explore all possibilities. But like other people on here, I wish there was a simple answer. But as we know, MS brings with it lots of difficult questions, and complex answers which are not what you want to hear at that moment in time.

Anyhow - I'll have fun explaining to my wife that we have to do everything but try and reach orgasms (at least for me) and then we can laugh again about how sex is so ridiculous. But thanks, Vicki. At least I have a plan now, which I was certainly missing before

Vicki - MS specialist nurse: I agree about the hideous slow pace of it all, but a careful construction of a strategy does enable one to feel that some action is taking place. There is nothing ridiculous about the loving relationship between you two. I think it is a wonderful one and a sense of humour is such an asset.

Mary C: I couldn't agree more that a sense of humour. I think is essential to a good sexual relationship

Ruth - psychosexual therapist: Yes, when we really add up what counts - it is sharing closeness and comfort that helps in the difficult days, and finding ways to gain, regain or keep the relationships we have as open, real and satisfying as possible is hard work but worth a great deal. Those relationships may not be 'Hollywood style' and we may not have partnerships but we can be supportive close friends and give warmth and encouragement to others. Sexual satisfaction is great but the value of friendship has to come higher.

Ruth - psychosexual therapist: Thank for letting me be here - have to go now

Vicki - MS specialist nurse: Bye Ruth. Great to have read your really useful advice

Simon - MS Trust: Ruth, thanks for your help this afternoon

Tony: I don't know if this is MS or an unrelated problem. My erection isn't affected by my condition, but I seem to have difficulty reaching orgasm. I wonder if this is something to do with reduced sensation or am I just attaching all my problems to MS?

Vicki - MS specialist nurse: This problem could be related to several issues. Again it may be a delay due to impaired nerve signals, it could be due to anxiety about performance or getting tired. Do you have stresses at the moment that might be affecting you in this way?

Tony: I suspect that part of the problem is that I'm anxious about the problem. I think Ruth's comment about friendship is very true. I wonder if the Hollywood myth of love and sex isn't part of the problem for some people. It gives the impression that good sex is all acrobatic contortions and toned bodies, rather than an expression of affection for someone you love that can take many non-acrobatic forms. I think my wife and I are quite loving and tactile. She says she isn't bothered by the problem (and it does make me last longer), but it niggles away at me sometimes.

Vicki - MS specialist nurse: This is so often the case. As we said earlier it doesn't take long for the 'chicken and egg' situation to get a hold. A couple more questions if that is OK. Are you in a relationship or looking to enjoy sexual satisfaction by yourself? Do you have worries in your day to day life that you may think you are coping with but actually are just able to sit on? Do you have good close sharing network, as Ruth mentioned?

Tony: Yes, I'm happily married (four years). As I say, my wife says this isn't a problem for her. I'm pretty OK with day to day life. Usual work concerns, but nothing unusually stressful. As for a sharing network - well, I'm a man. As a gender I'm not sure we're terribly good at sharing :)

Vicki - MS specialist nurse: You are so right about you blokes ! But you are doing brilliantly just now. If you are finding that you cannot control the worry then see your GP, as there are some medications that can help. Some women would say it is an asset because it allows them to achieve orgasm without the fear of rushing.

Mary C: I do workshops for women and if Tony has any ideas how I can get sexual education for the over 18's out to men let me know

Vicki - MS specialist nurse: Some workshops for guys would be very good I think.

Tony: I know I give a poor view of men, and I don't mean to sound cynical, but I suspect something reassuring that people could refer to in private and then subsequently give the impression that they weren't really bothered about it would fit the bill. I must admit that I like the fact that this is online. I'm not sure I'd turn up to an event or a workshop without a lot of persuading.

Vicki - MS specialist nurse: This is very useful information thank you. So an interactive package that could be accessed and backed up by an expert would fit the bill? Not a poor view of men for sure!

Vicki - MS specialist nurse: For everyone I would like to add a small list of some do's and don'ts' that are really useful when thinking about sex and what to do.

DO talk
DO listen
DO be flexible
DO vary lovemaking times, positions, touch, fantasies
DO use gels/vibrators (for dryness and for fun)
DO use high energy times and avoid low energy times
DO hold on to your sense of humour
DO go with the flow
DO hold off full penetrative intercourse whilst you are worrying and yet to get your plan completed
DO think of the wider picture not just the bedroom (we take a lot with us to bed!)

DONT avoid each other, or yourself
DONT avoid intimacy/affection
DONT avoid talking
DONT avoid touching
DONT blame
DONT have pre set expectations
DONT focus on penetrative intercourse as the sole target
DONT measure performance
DONT assume there is nothing to be done
DONT assume that it is all down to MS

Mary C: That is brilliant and so concise and true.

Tony: Thanks for the do's and don'ts. It's all basic simple stuff about getting along - but just the sort of stuff that gets so easily forgotten.

Tuppy: I would add to the Do's - try having orgasms from all the various parts of your body and at the same time. I would add to the Don'ts - don't be orgasm focussed.

Tuppy: How come nobody has mentioned cannabis? Not only can it make life bearable for some people with MS, it can be wonderful for sex because it heightens beautiful sensations.

Tom: Of course, I'd completely forgotten. We have been very rare users - but forgot the orgasm. When we have used it in the past and co-incidentally had sex, it was marvellous - we didn't care about orgasms at all, we just enjoyed the most marvellous time touching and looking at each other - and in fact, I 'came' without any genital touching at all, just through kissing, on one occasion.

So that's something else to add to my list of tasks - to find a local safe provider, and to try it again when day when we have time and it is conducive to being together for a while without any other worries

Vicki - MS specialist nurse: Thank you for that. Diversional therapy at its best. It helps to emphasise a very important point - shift the focus a little and sometimes it is just the thing you needed to do, as a solution emerges without effort.

But I am cautious not to be too glib about this. Sometimes much effort, expertise and experience is required to resolve our problems.

Tom: Yes - not to be too glib about it. In fact, though I do try and retain my sense of humour, the sexual frustration I feel, can be overwhelming sometimes

The fact that we do love each other, and after so many years, still desire each other and love having time together, is not enough compensation sometimes, for the loss of my sexuality. My sexuality has always felt like such an essential part of myself - I have always been a very sexual being, so to become suddenly, like an empty shell is difficult to cope with, no matter how much we want to do everything possible to cope with it.

But having this conversation and reading today's comments and those who write in, has at least made me not feel alone, and to realise that other loving couples can also have these problems.

Eve: My problem is that my husband has had an intimate relationship with another woman and I feel devastated. Has anyone else had a similar experience?

Gill: Oh eve, I am sorry. My partner eventually left me, but it was the MS not someone else that came between us

Vicki - MS specialist nurse: Hello Eve.

Many partners are trying to cope with the knowledge that someone else has experienced the physical aspect of the person they love, or are in a relationship with. It is a big issue and will have an enormous impact on your sexual relationship. You need to set out clearly what your reactions are, and what you are able to accept, not accept and how to continue (or not) with this marriage.

Then go and see a relate counsellor to consider and explore all the options. No pre judgments or decisions just yet.

Take care and remember that you are your own realm of what is normal and acceptable. Don't judge by other's standards of what is OK. So long as there is no harm to another you two must work out what is best for you both

Tuppy: Awful to be devastated, but I hope you can accept that most people do treat themselves to an affair now and again, and it's nothing personal. Lots of couples have open relationships because they don't want to be totally restricted to one person and you can look at it this way - allowing your husband to enjoy someone else is a gift to him. It's only sex, but you have love. You need to be very confident to share, and this is not easy when you have a disability. But some disabled people feel it is only natural for a partner to want an escape from disability now and then. Hope it all works out for you. I am sure it will.

Eve: That's one way of looking at it, Tuppy, but I wish I could feel more generous about letting him escape from my disability! I don't want to be escaped from!

Gill: Tuppy, I see what you say, but it does require a lot of strength to see life that way.

Vicki - MS specialist nurse: This is common. Some are simply not able to cope with the MS. But a friend recently said that she found a new freedom after some years in not being tied to another's' disappointment and inability to cope with her ms. So a new life with less burden is the way to see it.

Gill: I agree. I was terribly cut up at the time - devastated as Eve says - and it took a long while to get over it and stop blaming myself. As if I'd ruined things by getting MS. Now, a few years on, I see it as a good thing. It was the MS he couldn't cope with and frankly, that's part of who I am. It's was a horrible ride, but you do come out of it - eventually

Jane: So sorry to hear of your situations, Eve and Gill. My husband of almost 15 years left me for a younger model a while back. Yes at first I was devastated, but now I see it as the best thing that could happen to me. I now have a guy who takes my MS on board, but sees ME first :o)

Vicki - MS specialist nurse: Gill, I do hope that you can find a new freedom after the loss of a previous partner. Not easy I know but as a specialist who has watched people with MS get through incredible adversity I know you are a group who are courageous, inventive and full of surprises!

Gill: I'm not quite as lucky as Jane, but I do feel I'm facing the world on my own terms now in a way I don't think I ever did with my partner

Eve: I do blame myself, although I know it's not my fault. Are you still with your partner, Gill? I have thought of going it alone but when I mentioned this as an option, he was determined that he was going to stick with me and not leave me!

Gill: We split eventually. He wanted me to be the person I'd been five years previously, and I wasn't that person anymore. Maybe that would always have been the case, regardless of MS. I blamed myself. I ranted and raved, but eventually came to see that if he wasn't up to me, I was better on my own.

Vicki - MS specialist nurse: It is worth remembering also that one in three marriages fail in this country. One in three of the population don't have MS and

the reasons for a marriage not working may be many and best to let go of a 'dud'. The real firecracker may yet be out there. Thinking of our theme of sex in particular!

Gill: But Eve, the fact he still wants to stick with you is something to explore. As Tuppy said, if he's separated the sex and the love and you've still got the latter, that's potentially a good thing. Not easy, but maybe...

Eve: Another problem is that I feel I've driven him into someone else's arms by being difficult and horrible, but he insists that we are partners. We have enjoyed some more intimate moments recently but I do suffer a lot of pain and I do have the continence problem, so have welcomed some of the good ideas shared earlier.

Gill: Don't blame yourself too much. MS must have made me a nightmare at times, but we're none of us saints. Talk to him and find out what you both want from each other. It sounds as if you have a hope that I didn't have with my partner

Vicki - MS specialist nurse: Eve, I would like you to go and discuss your symptom management with your MS nurse, then spend a bit of time on your body with some beauty therapy, massage, new outfit etc. Then I would like you to enjoy a little time to yourself in terms of exercise and rest, recreational activity. Finally you can then go and discuss things with your husband on equal terms. No longer a victim - angry, guilty and with all the negative baggage you may be carrying. See what happens after that.

Jane: My boyfriend has never known me without MS, so I know he loves me for who I am now, not who I used to be. He's also far more open and experimental in the bedroom than my ex ever was!

Eve, remember that you have to do what is right for YOU. For me infidelity was a deal-breaker regardless. He did ask to come back at one point and I said no, which is tough when you have two young kids and a very uncertain future but I'm more than glad I stuck to my guns!

Eve: Thanks, everyone for listening.

Gill: Good luck, Eve. You'll get through this

Tuppy: Before this finishes, I would like to congratulate you all on this fantastic day of sharing. I hope the Sex and Disability Alliance can invite you to present the outcomes at one of our meetings.

It's so wonderful to see health professionals being so open, and people with MS being so trusting to discuss their intimacies. One day I hope there will be much more help and support for individuals, with sex being addressed as a matter of course with everyone who develops MS.

Simon - MS Trust: I'm afraid we're going to have to wrap the session up now. Thanks to Vicki for her input and to Nicki, Nolly and Ruth earlier in the day. And thank you to all the people who asked questions and shared their experiences.

Vicki - MS specialist nurse: Thank you everyone. It was meant to end at 7pm but has overrun a little. It has been a very great privilege to talk to you all. Thank you for sharing so much with me.

Further information

MS Trust Information Service

Spirella Building
Bridge Road
Letchworth Garden City
Tel: 01462 476700
Email: infoteam@mstrust.org.uk
Web: www.mstrust.org.uk

Links

The following links were mentioned during the chatroom. The MS Trust can not vouch for the products of information available and their inclusion here does not constitute and endorsement by the MS Trust.

Shops

- Ann Summers
www.annsummers.com
Shops throughout the UK
- Beecourse
01264 358853
www.beecourse.com - shopping
www.maryclegg.com - advice
- emotional bliss
www.emotionalbliss.co.uk
- nicesextoys
0870 744 6314
www.nicesextoys.co.uk
- Sh
020 7613 5458
www.sh-womenstore.com
shop at 57 Hoxton Square, London N1 (men can visit the shop but need to be accompanied by a woman)
- Vielle
01923 229 251
www.vielle.co.uk

Intrinsa

- Ardana – manufacturers of the Intrinsa patches
www.ardana.co.uk

Books

- **Sexuality and MS: a guide for women**
Nicki Ward-Abel
MS Trust, 2007
ISBN: 1904156118
- **The Sex Starved Marriage: a couple's guide to boosting their marriage libido**
Michelle Winner Davis
Simon & Schuster Ltd, 2004
ISBN: 0743252411
- **Rekindling Desire: a step-by-step program to help low-sex and no-sex marriages**
Barry McCarthy & Paul A Schroeder
Brunner-Routledge, 2003
ISBN: 0415935512
- **Perfectly Normal: a woman's guide to living with low libido**
Dr Sandra Pertot
Rodale International Ltd, 2005
ISBN: 1405077557

DVD

- **Beginners Guide to Tantric Sexuality**
Leora Lightwoman
New World Music, 2003

Information

- **BBC**
Sex and sexual health pages -
www.bbc.co.uk/relationships/sex_and_sexual_health/
- The Internal Clitoris by Dr Betty Dodson.
A four minute film available on You Tube
<http://digbig.com/4sttq>
- **Outsiders**
A community of people with physical and social disabilities who run a self-help club and campaign for the acceptance of disabled people as sexual partners
The Outsiders, BCM Box Outsiders, London WC1N 3XX (please send a stamped addressed envelope for more information)
Tel: 020 7354 8291
Email: info@outsiders.org.uk
Web: www.outsiders.org.uk
- **Sex and Disability Helpline**
Dr Tuppy Owens, BCM Box Lovely, London WC1N 3XX (please send a stamped addressed envelope with your enquiry)
Tel: 0707 499 3527 (weekdays 11am to 7pm)
Email: sexdis@outsiders.org.uk