



# **Sexual problems and pregnancy issues with MS**

**Chatroom**

**23 June 2003**

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

## Sexual problems and pregnancy issues with MS

**23 June 2003 – 10am to 7pm**

The experts:

- **Nicki Ward**  
*MS specialist nurse (10am – 4.30pm)*
- **Kate Watkiss**  
*MS specialist nurse (1pm – 4.30pm)*
- **Trish Allen**  
*Erectile dysfunction specialist nurse (3.30pm – 7pm)*
- **Dr Sandy Burnfield**  
*Retired psychiatrist with personal experience of MS (5pm – 7pm)*

If you don't have access to the internet and would like information on the websites and publications referred to in the transcript, please ring the MS Trust on 01462 476700.

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

**Rachel:** I am writing a dissertation on the effects of ms on a person's body image/ sexuality and wondered if you could suggest some useful articles?

**Nicki - MS Nurse:** Hi Rachel, I have got a reference list of articles that I am sure will be helpful to you as this is an area that I write/read about a lot. I lecture on this area as well. If you want to send your email address to [simon.webster@mstrust.org.uk](mailto:simon.webster@mstrust.org.uk) he will forward it to you later in the week. Is that OK?

**Rachel:** Fantastic! Thank you!

**Simon - MS Trust:** Hello Judith and Anne, do you have a question for Nicki?

**Anne:** Sorry, never done this before!

**Simon - MS Trust:** That's OK

**Judith:** I am going through the change and get very hot and cant get cool, any advice

**Nicki - MS Nurse:** Hi Judith, keeping cool can be a big problem can't it? My suggestions aren't rocket science but may help. Keeping a flask full of ice cubes may help especially if travelling in a hot vehicle, you can then keep sucking on an ice cube. Some people have invested in a ceiling fan in their bedroom that they can keep on constantly. Obviously the main thing is to keep your core temperature down so don't do anything that will raise your temperature too much such as strenuous exercise. I am sure you have thought of tepid showers. You may find sitting with your feet in cool water is helpful? There are cool suits but these are a bit pricey and the evidence that they work isn't great. The principle of the suits are ice blocks so I suppose as long as you don't put the ice block directly on your skin, but wrap them in a cloth and don't leave them on for too long this may be worth a try.

**Judith:** Thanks Nicki. I haven't been diagnosed too long but have found the MS Trust really helpful, and have only recently had access to the net.

**Anne:** Would like to recommend DPPi, now have a 20 month old baby girl, and although pregnancy is difficult it is possible with MS. DPPi is Disability, Pregnancy & Parenthood international

**Simon - MS Trust:** A good organisation, Anne. Their website is at [www.dppi.org.uk](http://www.dppi.org.uk) or ring 0800 018 4730

**Nicki - MS Nurse:** Hi Anne, I have heard about and read about the DPPi but have never had any direct contact with them. In what ways have you found them helpful?

**Anne:** The first point of contact for me was the Disabled Parent's Network, and I suppose it was a reassurance that I was not the only disabled pregnant woman on the planet! Both these organisations have informative newsletters and telephone/internet contacts.

**Nicki - MS Nurse:** Do you get regular newsletters from the DPPi? Have you ever phoned them for any advice? I am interested in the service they provide

**Anne:** Yes I receive the quarterly journal from DPPi, and have phoned for advice re. baby car seats for parent's with a mobility problem,

**Nicki - MS Nurse:** Judith, the chat room is quiet at the moment, do you have any other questions you want to ask?

**Judith:** I think I am still coming to terms with a total life change. I feel mad at times and ask why me? Do you think it will be long before I can come to terms with my disease? I went to see my doctor as I was feeling depressed but all he offered me was Prozac. Surely there is more than anti-depressants?

**Nicki - MS Nurse:** Judith, I suppose anti-depressants are a straightforward answer to doctors. A 'quick fix'. Doctors work on a medical model of care and like to be able to prescribe a treatment or a tablet. If they can't do that, some of them are at a loss to know what to do. There are a variety of other answers to try and help manage depression, involving encouraging you to take control of your life as MS can sometimes take that away. Also you may find complementary therapies may help you feel a bit better about yourself as well. The other important thing is that you have lots of things to look forward to and that you maintain contact with friends and family as much as you possibly can as support from them will be invaluable. Do you have an MS nurse in your area?

**Judith:** Yes I have an MS nurse who has helped me

**Simon - MS Trust:** Hello Geraldine and Margaret, do you have a question for Nicki?

**Geraldine:** I have a question, if I'm not butting in. My friend was diagnosed with MS 18 months ago. He's just 25 and extremely worried that ... how can I put this ... his sexual performance will be affected. Without any examples of it happening so far, does that mean he'll be OK?

**Nicki - MS Nurse:** Hi Geraldine, sexual problems in men are like other symptoms in MS, they can fluctuate and may even relapse and remit. On occasions they can develop and last constantly, but there is no real way of predicting what may happen to your friend. He may be fine and always be fine! In my experience of talking to people with MS about their sexual problems, there are often difficulties unrelated to MS such as side effects of drugs the person is on, relationship difficulties, performance anxiety and so on. These all have to be excluded first before we can definitely say the sexual difficulties are due to MS. If a man has sexual difficulties, eg erection problems, he may be prescribed Viagra, which has been proven to be effective in 75% of men with MS. Other management is down to a thorough assessment of the problem. MS nurses are good at assessing sexual problems and IF your friend develops problems he can contact his nurse. A bit of a long winded answer, but the important thing is that

he tries not to worry too much about what might happen as this in itself can affect his performance. He also needs to be careful of medications he takes, of smoking and drinking too much. All of these can affect performance

**Geraldine:** Thanks everyone for that answer. I'll try and talk to him about it - but then it's such a difficult area to broach even among friends.

**Nicki - MS Nurse:** You are right Geraldine, it is difficult. The main thing is that he knows he can talk to you about it if he needs to, a friend like you will be very important to him.

**Simon - MS Trust:** Hello Jeff, do you have a question for Nicki?

**Jeff:** Hi. I suppose my question is really a comment rather than a question. Having had bladder and bowel problems, it really puts a strain on the sexual side of my marriage. Any thoughts?

**Nicki - MS Nurse:** Hi Jeff Of course you are right. Bladder and bowel problems put a big strain on the sexual side of relationships. It is difficult to be intimate with someone if you are worried you are going to have an 'accident'. My advice as a nurse is that you have a thorough assessment from a continence nurse and she will advise you on this. You need to ensure that you have emptied your bladder and bowel prior to having sex, you may need to self catheterise for example or use suppositories. Have you seen a continence nurse? The other thing to be really aware of is that it often helps to talk to your partner about the feelings and fears that you have, are you able to do this?

**Jeff:** I have spoken to the continence nurse and she was very helpful and supportive. It's more of an emotional thing for me and my wife to get over, I suppose

**Nicki - MS Nurse:** That must be very difficult Jeff. And if you are feeling anxious that can affect your performance anyway

**Jeff:** True - it doesn't help either of us

**Nicki - MS Nurse:** One other thing I suppose is to have fun and a bit of a giggle when you are having sex to be able to take some of the anxiety away

**Jeff:** Good point, Nicki. It's easy to be so bothered by the MS that you forget sex is supposed to be fun

**Judith:** Thanks for listening, have to go now but will try to get back or speak to you next time.

**Simon - MS Trust:** Does anyone have a question about sexual problems and MS or issues relating to pregnancy?

**Jim:** The spirit is willing, but the flesh is weak, if you see what I mean. Anything that I can do? Anyone had similar experience?

**Nicki - MS Nurse:** Jim, are you saying that you have problems achieving an erection? Or is it your orgasm that is a problem?

**Jim:** Both really. If I do get an erection, orgasm is rare. Though often I don't do very well in getting an erection

**Nicki - MS Nurse:** Have you ever discussed this problem with a doctor or nurse? If so did they advise anything?

**Jim:** It's not a question I've found easy to talk about with people. Are there specialists or people I can be referred to? Or is this just standard stuff?

**Nicki - MS Nurse:** The most informed professionals to discuss sexual problems with are your MS nurse, your GP, your continence nurse or your urologist (this is a doctor who specialises in bladder problems, they also are experts in erectile dysfunction). Also at most Urology departments there are special erection dysfunction clinics that are run by very experienced staff who deal with erection

and orgasm problems all the time. Your GP or MS nurse will be able to refer you. I know it's embarrassing, but there are specialists out there that you can access and who may make a big difference to you. What do you think? Also Trish Allen a urology nurse from Sheffield will be here in the chatroom at 3pm, she may have further advice for you.

**Andy:** Early on when I had MS, I had some loss of sensation in the tip of my penis. I think this has resulted in some nerve damage. Erection can be achieved, but orgasm is very difficult. Is there a way I can encourage regrowth of these nerves? Is that possible?

**Nicki - MS Nurse:** Hi Andy, There isn't a particular treatment at the moment that will encourage the sensation to come back to your penis I'm afraid, but it is important to maximise your orgasm potential. You may need to use fantasy or guided images to help. Try thinking about what makes you feel sexy and then think these thoughts when you are having sex and just about to orgasm. You may want to talk about your fantasies with your partner or keep them in your head - it obviously depends on your relationship. You may want to use videos or sex toys. You may also find oral sex is a more effective way for you to achieve orgasm. It is important to discuss your problems with a professional (ie a nurse or doctor or continence advisor) who will be able to offer individual advice to you according to your circumstances. Also it is important that you are not taking any medication that may affect your orgasm. You may be able to take Viagra if you talk to your GP and you do not have any heart problems

**Jim:** I heard about another drug like Viagra becoming available. Can't remember what it was called. Is this about now or was it just the press jumping the gun? How is it different from Viagra?

**Nicki - MS Nurse:** Jim, thanks for your question about drugs to help erection problems. I need to have a look as I can't recall what it is. You are right though there is a new drug out. Give me a minute and I will talk to you about it

**Nicki - MS Nurse:** Jim, the drug is called Cialis and is produced by a company called Eli Lilly and Co. This drug stays in the system for 24 hours as opposed to Viagra, which only stays in the body for 3-4 hours. Another company called GlaxoSmithKline will also be producing a drug called Levitra later this year. I am unsure whether GPs are able to prescribe Cialis on the NHS although it is available on private prescription. You will need to discuss it with your GP

**Jane:** Hi. What would you say to someone who is asking why she can't have a spinal anaesthetic during the birth?

**Kate - MS Nurse:** There used to be concerns that epidural anaesthesia could cause a relapse, but this has since been disproven. Several recent studies have shown that epidurals are safe for women with MS. It is a good idea to discuss this with an obstetric anaesthetist before the birth.

**Jane:** This person was offered a spinal anaesthetic rather than an epidural

**Kate-MS Nurse:** As far as I am aware, spinal anaesthetics are given as a one off anaesthetic and can't be topped up like an epidural. Perhaps your friend was offered this because of the stage of labour? There is no difference between epidural and spinal anaesthesia on either safety or effects on MS

**Lucy:** I would like to ask the MS nurses whether during pregnancy both fatigue and bladder problems are a lot worse.

**Kate - MS Nurse:** Hello Lucy, how women with MS feel during pregnancy is very individual, and I have known several sail through with no effect on any of their existing symptoms. However, fatigue is very common in both pregnancy and MS, and so may well be worsened. Similarly, as the baby grows, extra pressure is exerted on the bladder, and if the woman has bladder symptoms because of her MS, then again, these can be made worse. So, although a woman may be very

well and have no extra problems, it is wise to be prepared for these things to happen so that plans can be made, and advice sought promptly.

**Lucy:** Thought so. But can you take oxybutynin again after 3 months?

**Kate - MS Nurse:** Oxybutynin is best avoided throughout pregnancy and caution has to be taken during breastfeeding as well

**Lucy:** Do you know many pregnant women who use wheelchairs and are there any tips on how to manage?

**Kate - MS Nurse:** Lucy, do you mean permanent wheelchair user? I have experience with women who are able to walk indoors but use a wheelchair outdoors

**Lucy:** I can walk a little bit but use my wheelchair indoors for safety.

**Nicki & Kate - MS Nurses:** Just because you are a wheelchair user doesn't mean that you won't be able to manage to care for a baby, but you would need to plan ahead as much as possible. There may be some practical difficulties, but there is a variety of help available, although this varies from area to area. An occupational therapist should be able to advise you, or there may be a disability resource centre in your area that caters for young mums with disabilities. Your MS nurse may also be able to help with advice on equipment etc. There are some good websites and organisations where you could get in touch with other mums in the same position, and get info on specialised equipment. A good place to start is DPPi - 0800 018 4730, web site [www.dppi.org.uk](http://www.dppi.org.uk). The National Childbirth Trust can also be helpful tel: 020 8992 8637. A good book is "Disabled Parents. Dispelling the Myths" by Michele Wates (ISBN 1-85775-257-0)

**Lucy:** Yes. I have been in touch with other disabled parents via email, which I highly recommend. Is stiffness a real problem or does it improve in pregnancy?

**Nicki & Kate - MS Nurses:** Once again Lucy, this is very individual. I have had some experience with women who were on antispasmodic medication (e.g. tizanidine) and had to come off prior to the pregnancy. We were worried that stiffness and spasms would be a big problem, but in fact the lady had regular physio and carried out exercises and didn't encounter any particular problems. We had to work with the physio to try out comfortable positions for labour that didn't trigger spasms in her thighs, and in the event, she coped very well. The best advice would be to speak to your GP, neurologist or MS nurse about your particular stiffness and medication.

**Lucy:** OK. I must go out now but thanks for your advice - it's been v. helpful. Bye

**Simon - MS Trust:** thanks for your contribution, Lucy

**Phil:** We were thinking of starting a family but my wife has been diagnosed with MS (last autumn). Her mother had MS and she has a cousin with MS too. We are now worried about passing it on.

**Nicki & Kate - MS Nurses:** Hello Phil, thanks for your question. The risk of your child developing MS is generally considered at 2-3% risk. Although this is slightly higher than the general population, it is still considered to be low. MS does on occasions affect one or more family members, but just because your mother in law has MS and so does your wife, there is nothing to say that your child will develop it too. We realise that this is a difficult decision to make but we strongly believe that having MS shouldn't necessarily put you off having children

**Phil:** Thanks for the info. And hearing other questions is useful too. A broad question, but are there any tips for making things easier for a mother with MS and a family with someone with MS?

**Anne:** How old is the baby?

**Phil:** There is no baby as yet. We're thinking about it at the moment - weighing up the situation

**Nicki & Kate - MS Nurses:** Phil, you are right, this is a very broad question. There are books and publications available which take on a broad approach that you may find useful, we have mentioned some of these already. Judy Graham has produced a book called ' Multiple Sclerosis and having a baby' (ISBN 0-89281-788-7) which is a good read. You may find this helpful. Have you a specific worry?

**Phil:** Fatigue is a worry. My wife has days when she's completely wiped out. A baby is hardly going to help with this. And the long term picture. How will she be when the baby is 10? Impossible to say, I know, but a big worry to us

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

**Bobbi:** Could I just listen for a while?

**Simon - MS Trust:** Please do. We'll be publishing a transcript of the whole session in a few days, so you'll be able to see everything that's been said

**Nicki & Kate - MS Nurses:** Phil, you are right, fatigue can be very disabling and has to be taken extremely seriously when planning to have a baby. One of the main sources of help tends to be family and friends. Do you have much in the way of support?

**Anne:** I did the same, it's a big step but definitely worth it! One tip from an OT was to get a rocking crib to soothe a crying baby (provided there is nothing physically wrong with him/her) and gently stroke the face to comfort the baby and make sure other carers do the same. This saves valuable energy, which is in short supply for a mum with MS, since you are not constantly lifting up the baby. My 20 month old daughter still responds to this since she has been used to this since birth.

**Nicki & Kate - MS Nurses:** Thanks Anne, it's helpful to hear your experience. You are quite right, many mothers find different ways of caring for their babies (there's rarely a wrong or right way). Babies seem to come through remarkably well, even with quite unconventional methods. It's tips like this from other mums that are so valuable

**Phil:** We moved here last year, so the local network is still a bit patchy. We have relatives not too far away (my sister, her brother). Haven't raised the idea of this with them yet but hope they'll be supportive

**Anne:** Babies are also very adaptable, I could swear my little girl is extra patient with me when I'm very slow.

**Nicki & Kate - MS Nurses:** Phil, sometimes people with MS who decide to start a family have to do a bit of educating with their family and friends. In my experience, once people are armed with the facts (e.g. pregnancy doesn't make MS worse etc), they usually rally and are very supportive. There might be some formal support available locally. In some areas the Health Visitor can arrange help from various organisations such as student nursery nurses looking for work placements, or in some areas there is an organisation called Home Start to help women with small children practically. It's worth doing your homework to help you reach your decision.

**Phil:** Thanks Nicki, Kate and Anne - this is helpful

**Nicki & Kate - MS Nurses:** Anne, I'm glad that your daughter is so amenable! I am involved with some women with MS who have very active toddlers, and still cope very well - some with extra support and help.

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

**Steve:** I have a problem with spasms if I lie in some positions - this can be very awkward. Are there any ideas that could help with this?

**Nicki & Kate - MS Nurses:** Hi Steve. Firstly you need to ask your neurologist whether you are able to increase your anti-spasticity medication. You may find that if you take an extra tablet about an hour or so before you have sex, this may help decrease the spasms. You do have to check with your doctor first though. You obviously need to vary the position you are in to have sex. Some people find that lying on their side is the most comfortable and reduces their spasms, but this will be unique to you. What do you think?

**Gail:** Hello Kate and Nicki. I am 24 years old and was diagnosed with MS last year. I am quite well in myself but am having some problems with the sensation in my vaginal area. I have a high sex drive but am not able to feel when we make love. This is really upsetting me. Can you offer any advice?

**Nicki & Kate - MS Nurses:** Gail, thanks for that question. There is no specific drug or treatment that is going to improve the sensation in your vaginal area. You may find that the sensation fluctuates like most MS symptoms. You need to maximise any sensation that you have, you may find that oral sex does allow you some sensation. Is this the case for you? You may also find that using a vibrator quite vigorously in your clitoral area is helpful. Some women find that using a vibrator anally is stimulating. There is also a technique called body mapping that may help; this involves searching the body for other erogenous zones such as your breasts etc

**Gail:** Thanks, but where do I get a vibrator from? I don't want to go to a sex shop as I will be too embarrassed

**Nicki & Kate - MS Nurses:** You're right, Gail, lots of women don't want to go into a sex shop. You are able to view and buy vibrators and other sex aids on the internet in reputable sites. The following are good to try; [www.annsummers.co.uk](http://www.annsummers.co.uk); [www.nicesextoys.co.uk](http://www.nicesextoys.co.uk); [www.sh.womenstore.com](http://www.sh.womenstore.com). The Family Planning Association also sell vibrators, their web site is [www.fpa.org.uk](http://www.fpa.org.uk). There are two female friendly shops which you may feel comfortable to go into. Ann Summers have several shops dotted about the country, the website will tell you if there is a shop near to you or you can phone them on 020 8645 8200. Also if you are in London, there is one shop of shwomensstore. No men are allowed in here. Their exact location is also on the web site

**Bill:** Can my partner continue to take beta interferon if she becomes pregnant?

**Nicki & Kate - MS Nurses:** Bill, this is a very topical question at the moment. Although there have been healthy pregnancies with women taking interferon, it is recommended by the pharmaceutical companies that you stop taking the injection three months prior to discontinuing contraception.

**Chris:** I've been taking Rebif for over 5 years. We had one child in 98, but have stopped trying for a second, largely due to my very low sperm count. My wife is convinced this is due to the beta interferon. Anyone ever heard of anything like this, or this problem in MS generally??

**Nicki & Kate - MS Nurses:** Hi Chris, MS is not in itself a cause of fertility problems in women or men. Rebif can slow the motility of sperm, but it does not directly affect fertility and is not the cause of a low sperm count

**Chris:** Thanks, I've not heard that before - do you know what the sources are? Is there any evidence of the Rebif damaging sperm motility?

**Oleg:** My penis loses its stiffness during the act. What can be done about it?

**Nicki - MS Nurse:** Hi Oleg, thanks for your question. There may be several reasons for this. Firstly it may be due to a medication you are on, such as anti-depressants or anti-spasticity medication. You need to discuss this with your GP.

It may be due to anxiety. Do you think this may be the case? Of course, it may be due to the MS and you need to speak to your GP or MS nurse about this as you will need a full assessment to see what your individual issues are. You may require medication to help maintain the engorgement of your penis. You may even need a penile implant although there are lots of things to try before then. Have you seen a Urologist?

**Jules:** hello - have I missed the pregnancy part of this chat?

**Simon - MS Trust:** No, do you have a question?

**Jules:** Yes, I am 14 weeks pregnant and although my MS is very mild, I have noticed my bladder is playing up a bit more than usual - anything you can suggest? The thing is, because I am pregnant I am going to the loo more often - and I find that when I stand up it's as if I haven't actually finished

**Kate - MS Nurse:** Hello Jules, congratulations on your pregnancy. It is important that you see your doctor or continence advisor about your change in bladder symptoms. You are right in thinking that pregnancy can affect the bladder in women with MS, but it is possible that you have a urine infection, or something else easily treated. You really need a bladder assessment including a scan, as it may be that your bladder isn't emptying properly. It is impossible to tell this just from listening to your symptoms - so the first port of call should be your GP, midwife, or, if you already have one, a continence advisor.

**Jules:** Thanks Kate - I was also wondering if the MS Trust has any leaflets or books recommended for MS and pregnancy

**Simon - MS Trust:** Jules, the MS Trust doesn't have a leaflet on pregnancy but there are resources. There's a book by Judy Graham called Multiple Sclerosis & Having A Baby (Healing Arts Press, ISBN 0892817887). The MS Society also has a leaflet. Contact their helpline on 0808 800 8000

**Jules:** Thanks Simon

**Kate - MS Nurse:** OK Chris, sorry it's taken a while to answer, but we've been getting the most up to date information direct from Serono who manufacture Rebif. There have been no specific tests done on spermatogenesis in men on Rebif, and although there were suggestions of motility problems in mice, there has been a large recent study on sperm production in rhesus monkeys (which are obviously more similar to humans than mice). They were treated with high doses of Rebif, and there were no problems identified with sperm production, motility or fertility. This is an area of ongoing research, and at the moment some neurologists do recommend coming off treatment if you are a man trying to add to your family. It's probably best to talk this over with your neurologist. Hope this clarifies things.

**Chris:** Thanks. I am in Hong Kong, and the neurologists and female fertility specialists I have spoken to here have no clue about it, other than to say the general weakening effect on the body of MS may affect the sperm quality, which sounds like reaching in the dark.

**Kate - MS Nurse:** Chris, we can definitely tell you that it is not the MS that affects fertility. Perhaps you should discuss coming off treatment for a few months with your neurologist - then at least you would have peace of mind that you had tried this option.

**Linda:** I'm experiencing reduced sensitivity during sex and a much less intense orgasm. If this is the MS, can it ever improve again, or in general does it only get worse?

**Nicki & Kate - MS Nurses:** Linda, you may find your problems are due to MS but without a assessment it is difficult to know. The problem may be temporary,

I know several women who find that this fluctuates and relapses and remits. Do you have an MS nurse?

**Linda:** No, I've only discussed it with my doctor and neurologist but they are vague and say its not possible to say. I was on Seroxat but came off three months ago to see if that was the problem, but its still there.

**Nicki - MS Nurse:** Linda, like all MS symptoms sensation can fluctuate. The best ways to improve your potential to orgasm is to use fantasy. Have you tried this? Are you on any medication at the moment?

**Linda:** I use fantasy, but I know there's something wrong physically and this is just adding to the depression.

**Nicki - MS Nurse:** Linda, do you have an MS nurse who will spend time with you discussing this?

**Linda:** Thanks, I was hoping to hear that it can fluctuate....this gives me hope!!! In the meanwhile I'm working on using my mind to consciously create physical reactions. I don't have an MS nurse but I will try to find myself one if you think they are more helpful!

**Nicki - MS Nurse:** Linda, a MS nurse is specially trained to help you in this. If she can't answer your questions, unfortunately there is not always an answer. There may be someone in your area that is more specially trained...

**Nicki - MS Nurse:** Linda, If you need to know who is the MS Nurse in your area, contact the MS Trust on 01462 476700 and they will be able to put you in touch

**Linda:** Of course I understand there may not be an answer (how easy that would be!) but just knowing that things can fluctuate in respect to this is already a big help. I'm living outside the UK but there must be the equivalent of MS nurses here! Thanks so much for your input.

**Simon - MS Trust:** Linda, where are you?

**Linda:** Amsterdam. I think one of the hospitals here has MS nurses, but its not the one I go to.

**Simon - MS Trust:** Have you been in contact with the Dutch MS Society? Their email is info@msvn.nl or ring (31) 70 374 7777.

**Linda:** Not yet, but I will. I've been kind of avoiding it (guess I have still a bit of an 'acceptance' problem!) Thanks a lot, Simon!

**Chris:** MS apart - is it common for sperm quality to deteriorate? I am 39, no other conditions. On another subject - I find less sensation during sex, so use Viagra to maintain an erection, which works, but ejaculation in normal sex is difficult - any ideas?

**Linda:** Have to go now. Thanks again for your responses!

**Simon - MS Trust:** Thanks for your contribution, Linda

**Kate - MS Nurse:** Chris, it is accepted that as men age there may be a slight decrease in fertility, but as you know, many men father children late in life. Apparently there has been a decline in male fertility generally over the past 20 - 30 years, and this is thought to be due to lots of reasons including environmental. I presume you've tried all the usual advice (boxer shorts, giving up smoking, cutting down alcohol etc)? Obviously if you having difficulties ejaculating, this will affect conception. You need to increase your capacity to orgasm and you can do this through using fantasy, vibrators, sex aids, or erotic videos. You may need more vigorous stimulation and perhaps penetrative sex isn't enough. You may find oral sex is more satisfying for you. You may also find that if your partner uses a lubricant, or you use one, something like Sensilube by Durex, this may help the sensation as well

**Chris:** Wouldn't lubrication by partner merely reduce sensation?

**Nicki - MS Nurse:** Hi Chris, no lubrication won't reduce sensation, it may enhance it.

**Simon - MS Trust:** Trish Allen, an erectile dysfunction nurse has now joined the session and will be with us until the close at 7pm

**Kegaz:** I'm 47 with ppms. I have an indwelling catheter. I have received lots of negative views on intercourse? Any advice? I found body mapping revived my sex life.

**Kate - MS Nurse:** Hello Kegaz, has having an indwelling catheter put you off having sex, or is it your partner that has an issue?

**Trish - erectile dysfunction nurse:** It is possible to have sex with a catheter in situ. The catheter can be folded carefully back along the shaft of the penis and a condom rolled over both it and the penis. This will secure it. Plenty of lubrication can then be applied. I am assuming that I am speaking to a man here, but it is also possible for a woman to secure the catheter up the front of the abdomen with tape after removing the bag as with the man, and using lots of lubrication. I have also known of patients who want occasional sex to have it when the catheter has been removed at the usual time, and before the new one is inserted. Gentleness is also essential!

**Kegaz:** Has not put partner off at all, I think its me - I'm scared. Have not had erection since it was put in. Scared about using Viagra. Everyone seems to skirt around the subject. I am awaiting for a suprapubic catheter, which no doubt will be better, but no one will talk about sex and indwelling catheters

**Kate - MS Nurse:** Having an indwelling catheter doesn't mean that you have to avoid sex, although we often recommend a suprapubic catheter for people who are sexually active. I'm sure you will find this better. Why are you scared of using Viagra?

**Trish - erectile dysfunction nurse:** Yes, a suprapubic catheter will be much easier to manage!

**Kegaz:** I used Viagra successfully before I had catheter. Think I'm just scared of having an erection with the catheter - the unknown. I suppose it's bite the bullet and try it and see what happens! Plenty of lubrication before putting on condom

**Kate - MS Nurse:** Kegaz, you can't cause yourself (or your partner) any damage using Viagra with an indwelling catheter, although I appreciate what you are saying about the unknown! If you are that scared, why don't you try a half dose first time?

**Kegaz:** Will it put excessive pressure on urethra? Or just uncomfortable? Why is it such a taboo subject!!!

**Kate - MS Nurse:** Kegaz, it shouldn't hurt, although it may be a slightly different sensation to what you are used to. It isn't really a taboo subject, but many people don't know the answers to your question or don't even think about asking patients about their sex life. Also this is a time consuming subject and there may not always be time.

**Kegaz:** Its strange that as soon as you have some disability, sex is the one thing that everyone assumes you don't need!! And shouldn't. Hopefully I'll get suprapubic catheter soon and normal sex life can resume. Thanks for the information - you've all been very supportive and I have finally have had some answers instead of people quickly changing the subject

**Simon - MS Trust:** Not actually dealing with the practicalities of your enquiry, Kegaz, but our last newsletter (Open Door) had an article by a chap with MS discussing the importance of sex

**Kegaz:** I read that article with interest. In fact both myself and partner found it very interesting. That's why I've come on today

**Jules:** Typical British reserve!

**Simon - MS Trust:** Quite so, Jules (the author of the article is American)

**Jules:** :) at least a few people here are going through similar situations

**Kegaz:** Thanks. Hopefully speak again later or on your next chatroom session – bye.

**Chris:** Do you have any ideas on how to revive sex life between my wife and I which has almost stopped completely?

**Nicki - MS Nurse:** You need to establish intimacy with your wife and perhaps you need to talk and enjoy each other's company again. Perhaps you could find a baby sitter and take your wife out on a romantic date and court her again! Humour is very important and if you can have a laugh together it can sometimes restore a sense of closeness. Your wife may be exhausted with looking after your five year old. Variety is very important. What would make her feel more sexy towards you? Have you asked her?

**Chris:** What do people think, if anything, about visiting sex workers who may have experience with these problems? I heard about this happening in Australia.

**Nicki - MS Nurse:** Sorry Chris, I don't know anything about sex workers although I know they exist

**Simon - MS Trust:** Hello Aaron

**Aaron:** Are the MS nurses involved with the risk sharing scheme?

**Simon - MS Trust:** Aaron, the nurses are just going I'm afraid. Do you have a question about the scheme? If so, email it to [info@mstrust.org.uk](mailto:info@mstrust.org.uk) and we'll try and answer it for you

**Aaron:** OK thanks, Simon

**Simon - MS Trust:** Nicki and Kate have left the room now. The expert online at the moment is Trish, an erectile dysfunction nurse

**Jules:** I have heard that people should take aspirin prior to long distance flights - do you know if it is OK to take when pregnant - I thought there were contraindications

**Trish - erectile dysfunction nurse:** I would avoid any medication when pregnant but there are measures you can take on long flights which are safe - one is wearing stockings which can be purchased in chemists I believe. And also drinking lots of water helps too. Getting up and walking every couple of hours would be beneficial too

**Chris:** Trish, do you have any general advice to men with MS-related reduced sensation, ejaculation and other common sexual issues?

**Trish - erectile dysfunction nurse:** Chris, Loss of sensation is a real problem in some men with MS and unfortunately often difficult to treat. However, there are some medications that can help with ejaculatory problems associated with the condition, but you would need referral to a specialist centre to get this treatment if it were considered appropriate. I don't know how this works in Hong Kong

**Chris:** Thanks Trish. Could you mention what types, maybe I already have them?

**Trish - erectile dysfunction nurse:** We use yohimbine sometimes

**Chris:** Got to go, it's late here. Thanks and bye.

**Trish - erectile dysfunction nurse:** Chris, thanks for your questions

**Simon - MS Trust:** Sandy Burnfield has now joined the room

**Dr Sandy Burnfield:** Hi everyone!

**Jules:** Do you agree Sandy - no aspirin in pregnancy? I am concerned about DVT - my grandmother had a thrombosis, I have MS, am 14 weeks pregnant and about to fly to the USA

**Dr Sandy Burnfield:** You should discuss this with your GP - he or she may prescribe aspirin in view of your particular medical history

**Jules:** OK thanks. Is there anything else I should be aware of? I already have two children, although I had not been diagnosed with MS then. I have just ordered that book you recommended Simon

**Dr Sandy Burnfield:** The usual - no smoking, keep a slim as you can and have your blood pressure monitored by the practice nurse

**Jules:** Thanks for your help

**Dr Sandy Burnfield:** OK Jules

**Sam:** Hi. I've found that over the last few years I seem to be getting less and less sensation during sex. Is this common? Can anything be done? I've felt a bit wary of mentioning this in case it wasn't MS but me

**Dr Sandy Burnfield:** Both men and women can experience sensation loss during sex. MS could be a cause, but so could other things, so best to talk to your doctor about it

**Trish - erectile dysfunction nurse:** If you are having ejaculatory problems then it obviously may affect your ability to father a child. If so you would need to seek specialist help. Is there anything else that's worrying you?

**Sam:** Fatherhood (or not) is not an issue, but it does mean that sex is less enjoyable for me

**Trish - erectile dysfunction nurse:** This is a very common problem in patients with MS and unfortunately there is very little that can be done to improve this. I would say this is associated with your condition, and if you are worried you could obtain a referral to a specialist centre to have this confirmed. There are new treatments that are being developed all the time though, so maybe in the future we will have something that can offer more help

**Sam:** A specialist MS centre? Or somewhere specialising in these sorts of problems?

**Simon - MS Trust:** Hi Alex

**Alex:** Hi. I was just hoping to hear how people cope with sex and the effects of MS

**Sam:** I find that it seems to have taken away sensations and made it less enjoyable

**Alex:** Is it painful?

**Sam:** No, not painful. In fact not anything. With reduced feeling it seems to have taken some of the enjoyment away

**Trish - erectile dysfunction nurse:** This is, as I say, an unfortunate part of your condition. The specialists are in erectile and sexual dysfunction. Where do you live?

**Sam:** Northampton

**Alex:** I find fatigue can be a problem for me (and thus for my poor amorous husband). We used to have a good sex life, but now I really have to pick my moments

**Trish - erectile dysfunction nurse:** Sam, I don't know anyone near you that does this type of work but you could ask your doctor if he does. You would need a referral from either him or your MS specialist

**Sam:** Thanks Trish

**Dr Sandy Burnfield:** Alex, fatigue can be reduced by being cool eg not too many bed clothes, lukewarm showers and bath, sex in the morning when you are fresh. Some medications are available, so worth discussing with your doctor or neurologist

**Alex:** Thanks Sandy. Put like that, sex in the morning sounds nicely decadent :-)

**Dr Sandy Burnfield:** Yes MS gives you a reason experiment and have different sorts of sexual fun!

**Trish - erectile dysfunction nurse:** Tiredness is another major problem. Not just with your condition. It seems the fast rate of life catches up with people in all walks of life! Kissing, holding hands and touching are vital to maintain intimacy when the full sexual act is not possible for whatever reason. In my experience, it is what is missed most when the problems start!

**Alex:** Does Viagra work for women? Is there a female equivalent?

**Dr Sandy Burnfield:** I think the evidence is that it can help some women

**Trish - erectile dysfunction nurse:** Alex, research is being carried out at present to see if it will help, especially in conditions like diabetes. Whether it will help in MS, I don't know. We'll have to see. There is a drug called Uprima that is also used for men, which is being looked at to see if it will help some sexual problems in women. Unfortunately there is very little we can offer women generally, especially with arousal problems - we are complex creatures!

**Alex:** Thanks, Trish

**Mick:** I take Viagra, which is very successful, but I don't always ejaculate. Is this common?

**Dr Sandy Burnfield:** Mick, I think that this is not uncommon but Trish would know more than me

**Trish - erectile dysfunction nurse:** Problems with ejaculation can be common in MS. There are various medications to help treat this but you would need to be referred to a specialist in sexual difficulties to see if they would be appropriate

**Alex:** Hi Ellie

**Ellie:** does MS directly affect libido in women? Neurologist said No I said yes!

**Dr Sandy Burnfield:** Libido is very complex but women with MS do commonly experience problems with it - you are right!

**Ellie:** Guess at 69 I shouldn't worry too much but it only hit me at 60 and then almost overnight!

**Alex:** I've always assumed it was me and the rest of life with MS stopping me getting in the mood. Interesting that it might actually be directly due to MS

**Ellie:** I feel sure it is, perhaps its just hormones

**Dr Sandy Burnfield:** Ellie - good for you! I am sure you can still enjoy touch, kissing and foreplay even if you don't go all the way.

**Alex:** Can't see why it should be different at 69 to 29 :-)

**Ellie:** No really, just went off the idea, overnight. I think hormones are greatly affected by MS, or the other way round

**Dr Sandy Burnfield:** You are right again, Ellie- but again it is a very complex area and no one yet understands this subject fully.

**Ellie:** I am sure they don't. My hubbie does not, that's for sure

**Dr Sandy Burnfield:** Pregnant women often feel good during pregnancy and are less likely to have a relapse - and menopause can be associated with a less severe course in MS

**Sam:** I've found I've been going off sex too (at 45) - though the reduced sensation is the thing. The lack of urge followed on from that

**Ellie:** Sam, that is just what I mean, you don't feel anything. My GP told me to lie back and think of England

**Sam:** England! Heavens, that would put me right off

**Trish - erectile dysfunction nurse:** Female sex drive and arousal is a very complex thing and many factors can affect a woman's sex drive. Not sure, I have to say.

**Ellie:** I was diagnosed during the menopause, was really bad. I was certainly good during both pregnancies, and also felt very well, but first attack was one year after first child

**Dr Sandy Burnfield:** MS is a complex and unpredictable disease - there are lots of exceptions to the usual patterns

**Ellie:** Yes I know, and think some of it is in my head, I don't feel very active, and feel loss of function and sensation is a failure, even at my age

**Dr Sandy Burnfield:** Ellie, you sound anything but a failure - but it is very normal to feel like that sometimes

**Sam:** Trish, excuse my ignorance, but can you tell me what an erectile dysfunction nurse does. I'd not heard of them before this chatroom

**Trish - erectile dysfunction nurse:** I work in a multidisciplinary team and I assess patients with erectile difficulties and after brief counselling, offer them various treatments, such as oral medications, other drug treatments and vacuum devices. I am a trained psychosexual counsellor but don't do in-depth work - my colleagues do that! It is a very interesting demanding and rewarding career which I still love doing after many years

**Simon - MS Trust:** Hi Pete, do you have a question for Sandy or Trish?

**Pete:** Hi. Just looking to see what was being discussed

**Mick:** What are your thoughts & comments on two people who both have MS trying for a baby?

**Dr Sandy Burnfield:** Mick, there is likely to be an increased genetic risk of the baby one day getting MS, so it would be worth being referred to a genetic counsellor in the NHS who would work it through with you both

**Simon - MS Trust:** There are also issues around childcare once the baby is born. The MS nurses who did the start of the session (which you can read in the transcript that will be available in a few days) made the point that people with MS should plan the support mechanism (family/friends who are willing to lend a hand) carefully before the baby is born

**Ellie:** Sandy, is there a gene which can be identified in MS and tested for in offspring?

**Dr Sandy Burnfield:** There is no one gene but indications are that there are several genes interacting - no specific gene has been identified

**Pete:** I wonder if anyone has any ideas for me. I have rather restricted mobility now and use a wheelchair all the time. Performance sex-wise isn't too hot at the moment. Is there anything that can be done or is it time to develop outside interests :-)

**Dr Sandy Burnfield:** Pete, lots of experimenting can be done if you are both interested - also new positions and some medications like Viagra. But sex is not compulsory yet!

**Alex:** Hi Pete. How does your partner feel about this? Is she supportive?

**Pete:** We seem to have got past the difficult patch and she's wonderful. But I do feel as if I'm letting her down as a husband sometimes - not just with the sex, but also the way MS is with me.

**Trish - erectile dysfunction nurse:** A great deal can be done nowadays when a man's ability to perform declines. Do you feel the restricted mobility is the problem?

**Pete:** It certainly doesn't help. It makes it difficult to feel ... well sexy. As I say, my wife is wonderful and loving, and I think this is more a problem for me. It's hard to be the person you want to be sometimes

**Alex:** Maybe you shouldn't try to be the person you want to be. Maybe you should settle for being the person your wife loves. Does that manage to sound both brutal and gooey at the same time?

**Pete:** LOL. No, it sounds sensible - albeit difficult to achieve sometimes :-)

**Trish - erectile dysfunction nurse:** Pete, coming to terms with the disabilities that your condition creates can often be very difficult in itself - so much change has to be dealt with, including bodily changes. It sounds though you have a wonderful wife who loves you dearly. Just remember you are the same man who is coping - well it seems to me - with your situation.

**Pete:** Thanks Alex and Trish. Maybe I'm just a bit down today. Thanks for your advice

**Simon - MS Trust:** We'll have to wrap up the session now. Thanks to Trish and Sandy, and to Nicki and Kate earlier in the day.

**Alex:** Thanks all. Bye

**Pete:** Thanks