



# **Young people, lifestyle and MS**

**Chatroom**

**15 April 2008**

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

# Young people, lifestyle and MS

15 April 2008 - 10am to 7pm

- **Emma Greenfield** - *MS specialist physiotherapist*
- **Nicki Ward-Abel** - *MS nurse*
- **Kate Watkiss** - *MS nurse*
- **Liz Watson** - *MS nurse therapist*
  
- **Julie Howell** (Jooly's Joint)
- **George Pepper** (shift.ms)

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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](mailto:infoteam@mstrust.org.uk)

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**Simon - MS Trust:** Welcome to the chatroom on young people, lifestyle and MS. The topic today is the effect of MS on people in their twenties and thirties - a period that also can include higher education, decisions about jobs and careers, about buying a house and about starting a family. How has MS affected you during this time?

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**Wez - Member of Team Fancy Pants:** Hello team MS Trust! Emma do you deal with fitness and stuff?

**Emma - MS Physio:** Advising on fitness and exercise is a part of what I do in my role. I also help people rehabilitate following relapses and manage ongoing symptoms.

**Wez:** Thanks Emma. I go to the gym four times a week and when I have a really intense CV class I normally find I have to come home for a sleep. Is that normal or am I just being lazy?

**Emma - MS Physio:** It's great that you are exercising regularly. As you probably know, fatigue is something that affects many people with MS. It sounds like you aren't being lazy but experiencing some fatigue. Do you feel refreshed following you sleep and able to continue with your day?

**Vonnie:** It is never lazy to take a rest after exercise, it's called listening to your body! With MS, bodies tend to give messages that need ignoring, but resting after exercise is a way to keep you going! Well done and keep it up!

**Wez:** Yes it's like a full body stretch. Once I have 30 minutes shut eye I'm fine. I'm going to run 7K today on the treadmill. I'll come back home shower then sleep then I'll feel great after. I'm gonna get this elusive 6 pack!

**Emma - MS Physio:** The fact that you feel fine after the sleep is great. If you are happy to manage the fatigue this way then I would encourage you to continue. If you were not getting the relief following your sleep then I might suggest that you looked at modifying your exercise routine but it seems you have things pretty sorted at the moment.

**Wez:** I bought a couple of the cool bandana things to wear down the gym. Have you heard of those?

**Julie - Jooly's Joint:** I used to sell the cool bandanas. I know a lot of people who find them really good. You soak the special bandana in water and the crystals in it soak the water up. The process of evaporation can cool the skin and feels quite good if you are really hot. On the rare occasions we have summer in the UK they can be useful too. ;-)

**Emma - MS Physio:** The cooling bandanas are one type of several products on the market which aim to reduce overheating and therefore the effects of fatigue. Some people find these useful when exercising.

**Geoff:** I've tried cooling scarves. A great help in the sticky weather

**Wez:** I had to order mine from America! Do people sell them in the UK?

**Simon - MS Trust:** We ran an article on staying cool in the Open Door newsletter. This has a few links to suppliers. You can read the article [here](#)

**Wez:** I have a nice little routine going and it involves more sleep if I feel tired. The world will still be there trying to charge me taxes when I wake up so I figure another 30 minutes won't hurt. I also use protein shakes and recovery drinks, is there anything I should avoid?

**Emma - MS Physio:** As far as I know there isn't any evidence to say you shouldn't use the protein shakes and sports drinks. As far as other supplements, etc go, I would suggest you discuss this with you GP or consultant as and when you think about using them.

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**Miriam:** Hi - I was given a definitive diagnosis last Friday - one of the most emotionally difficult consequences is 'the future unknown...'

I questioned my consultant with regards to stress. He seems to think that stress plays no part in triggering attacks. I'm not sure I agree as I was really stressed when I was hospitalised in December with a severe attack. I hope that if I reduce stress in my life that I will reduce the potential onset of future attacks - he disagrees...

Any thoughts on physical emotional stress and attacks?

Thanks

**Simon - MS Trust:** Miriam, thanks for the question. The not knowing where MS might take you is such a challenge - particularly when someone is recently diagnosed

**Julie - Jooly's Joint:** Hi Miriam, stress isn't good whether you have MS or not. Many people with MS do find that stress can lead to poorer health but it really depends on you as an individual. We're all different. You can have a relapse during a time when you're not stressed so there isn't necessarily a direct link.

If you're stressed this can lead to trouble sleeping and this can impact on your health in a bad way. And one person's stress is another person's pleasure. Personally, I find boredom stressful. People around me have long given up telling me to slow down.

**Nicki - Lecturer Practitioner in MS:** The issue of stress and relapses is an interesting although complicated one. There is literature that says stress can induce an attack, although that is not to say that every doctor agrees with this. I have people who say that stress affects them, I also see others that have been through the worst stress imaginable but do not have a relapse despite this

**Liz - MS Nurse:** This is a very interesting and much debated issue. There has been lots of discussion over factors such as stress and trauma increasing the chances of having a relapse. Studying this area is always difficult. However, the current evidence suggests that stress and trauma do not increase the likelihood of having a relapse. However, it is often clear that existing symptoms are often worsened during times when someone is particularly upset or stressed.

**Nicki - Lecturer Practitioner in MS:** Julie is of course absolutely right, I suppose the important thing for you Miriam is to look for ways to address the stress you are experiencing, although of course this is not always easy

**George - shift.ms:** Whether stress can cause attacks or not, I always feel better when I'm calm. when I get stressed I find exercise can really help

**Geoff:** Agree with your comment George. If things get on top of me, I find getting out into the open helps. You spend the first ten minutes mulling over the problem and then the mind wanders ... Or is that just my mind :-)

**George - shift.ms:** Yes, a change of scenery and a bit of fresh air can often help me

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**Hannah:** Hello, I have been given the diagnosis of primary progressive MS and I am 26! I have been seen by the neurologist since 2003 and my symptoms are mainly stiff jerky legs and spasms, and bladder problems. I have been married for nearly five years and have a three year old son. My husband is very supportive but our social life together is suffering due to my loss of confidence in my bladder. I cannot drink because it irritates it. I am being seen by a urologist who is now suggesting a cystoscopy. What does this involve and is there anything else I could try instead?

**Liz - MS Nurse:** Do you have an MS Nurse locally and/or have you been put in touch with local Continence Specialist Nurses?

**Hannah:** I was seeing a continence specialist but was only prescribed a few different tablets, which each time ended up with a water infection. My most recent one is oxybutynin but I don't really notice any difference by taking it or not. Is there another treatment using a machine with electronic vibrations to strengthen the bladder?

**Liz - MS Nurse:** There are lots of different treatments and interventions available which are usually recommended once all of the relevant questions have been asked and the various tests performed. It sounds like you are already in the system and under the relevant team at the moment. Hopefully once your specialists have all of the information about your symptoms and problems they will be able to offer you all of the treatments and/or interventions suitable for you. For the tests that have been mentioned NHS Direct online gives fairly detailed information and if I were you I would prepare a list of questions to ask your specialists when you next see them.

**Hannah:** I am waiting for the date of my cystoscopy at the moment, but I think my MS nurse is referring me back to the incontinence people again as well.

**Alison:** I have bladder problems and my neurologist has given me some medication called tolterodine. I've been on them three weeks and they have certainly worked for me.

**Nicki - Lecturer Practitioner in MS:** There has also been some great results with botulinum in the bladder, has anyone had this treatment?

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**Hannah:** I am not allowed to drive at the moment because of an operation - are you able to advise me on how I can get access to a mobility scooter?

**Emma - MS Physio:** This is something that varies from area to area and I know that here in Bradford our wheelchair services don't provide scooters. We will sometimes direct people to the local MS Society branch or to agencies such as Disability Equipment Bradford (previously DIAL). As I say, this sort of thing varies hugely from area to area and so your MS nurse or neurology team may be able to provide you with local contacts.

**Hannah:** Thank you Emma, will ring through now.

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**Louise V:** I'm 27 and I was a chef. I was diagnosed in August 2004 and retired in March 2005. I never suffered with heat before stopping work (luckily!)

**Julie - Jooly's Joint:** It's a strange thing, heat. Many people with MS can't take heat and can't take a hot bath or shower. I find heat doesn't affect me in that way. I've even worked in Dubai and was fine and hot baths are one of my favourite things to do.

I think with stress and heat and exercise the same thing applies - the longer you have MS the more you settle into 'your MS self'. You will develop an instinct for how far you can push it and what is good and bad for you.

I've had MS for 17 years now (nearly half my life). I just factor it in now and dealing with potential stress, heat, tiredness does come quite naturally to me now.

**Louise V:** Hot baths were also one of my favourite things too. I take care in hot weather- cold drinks, fans etc. However my mobility is too poor to get in/out of bath. C'est la vie!

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**Louise V:** A fatigue management course helped me to stop stressing out. It basically is planning your time and fitting rest breaks in. My MS nurse referred me.

**Simon - MS Trust:** Nicki, weren't you involved in setting up a fatigue management course in Birmingham?

**Nicki - Lecturer Practitioner in MS:** Yes, I run fatigue courses at the hospital I work at in Birmingham. They seem to work really well for some people. It is six weeks in length. People attend each week for two hours and we do different activities each week. People also like to share advice and tips with each other and find this really helpful. At the end of the course, we also encourage people to set themselves three or four goals that they will do to change their lifestyle and change their fatigue levels

**Geoff:** I did one of those courses (not in Birmingham). Really useful, but you have to be strict with yourself about following the helpful advice - so easy to slip

**Liz - MS Nurse:** The MS Trust has published an excellent booklet called 'Living With Fatigue - Fatigue Management for People with MS'. I often provide and refer to this when working with patients on their fatigue management.

**George - shift.ms:** Fatigue is my biggest problem, I've learnt that having an appropriate amount of rest is really beneficial to me eg if I sleep too much in the afternoon (more than two hours) it really affects my sleep at night. However, without an afternoon rest, I can feel wiped out the next day. Everyone's different so best to find your right level by trial and error.

**Nicki - Lecturer Practitioner in MS:** Sleep is interesting and there seems to be a certain amount of literature in the press about MS and sleep issues. Lots of people with MS have problems sleeping and sometimes as a nurse I work with the patient to see if it is sleepiness or fatigue that is the issue

**Geoff:** It's a balance, isn't it. Too much sleep and I'm dopey and too little and I flake out and am no good to anyone

**Nicki - Lecturer Practitioner in MS:** Yes, it is getting the balance right between sleep and exercise. Some people feel they shouldn't exercise as it would make them too tired. Like everything its balancing it all out

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**Julie - Jooly's Joint:** You can get in a vicious cycle with sleep and stress. These days I try to UNDER commit and OVER deliver. Stress can be caused by OVER committing and then feeling bad about letting people down, so I try to do the opposite. And just... be nice to yourself. Give yourself a break... don't take on other people's nonsense. Get into a habit of listening to your own body. You do know it best.

**Nicki - Lecturer Practitioner in MS:** I must admit when I am stressed I like to go up the football match or watch it on TV (big West Brom supporter) and have a good old shout!

**George - shift.ms:** Leeds Utd make me more stressed!

**Nicki - Lecturer Practitioner in MS:** George, you have just made me laugh so much! What a great stress reliever that is too!

**Alan:** It's similar to what someone earlier about going for a walk. Going to a match and shouting at the game is such a great release. A couple of hours outside the everyday.

**Louise V:** This very sad thing to admit to but I rant at the television - especially politics! I even wrote to my local MP in 2006 about cutting specialist nurses

**Alan:** Nothing wrong with ranting at the telly, Louise. It seems impossible not to much of the time! And I'm all for bothering MPs when stupid cuts are being pushed through

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**Andy:** Hi, does anyone have any info on the possibility of remission in pregnancy and the use of 'oestrogen' type substances for treatment?

**Nicki - Lecturer Practitioner in MS:** The science about MS and pregnancy says that relapse rates are lower during pregnancy, particularly during the third trimester. Then there is a bit of a rebound effect. Once the baby is born and oestrogen levels drop, there is an increased risk of relapse for the first three months after delivery.

There has been research looking into oestrogen to try and reduce relapses but the evidence is not conclusive so it is not something that can be prescribed. It is certainly a fascinating subject though and work is ongoing in this area

**Andy:** It does seem to be an area worthy of study, just a pity that tests, trials etc. take so long before any type of offerings become available.

**Nicki - Lecturer Practitioner in MS:** I can understand that. There is often a big buzz in the press about a certain drug and treatment and we all get excited and then find it has only been tested on mice! All very frustrating

**Andy:** Surely oestrogen has been tested before - HRT for example during the menopause?

Are there any stats out there for the effect of HRT on MS sufferers?

**Nicki - Lecturer Practitioner in MS:** The trouble is that giving oestrogen artificially can cause other complications - you may recall the HRT and increased breast cancer risk. Although this risk is low, this indicates obviously the potential problems of giving people additional oestrogen.

It sounds straightforward that if pregnancy protects from disease progression, why can't we induce that affect? It is being looked at though.

There are some trials out about HRT and MS. One that was done a little while back said HRT was helpful, although others disagree. Again interesting but not straightforward as we would like it

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**Will:** We're thinking through the pregnancy thing at the moment. My partner has MS and is OK with the relapse risk. What concerns us is the next few years eg fatigue levels and maybe some other twist of her MS that makes looking after a lively child a challenge. Anyone been through that and got any advice?

**Hannah:** Hi Will. I have a three year old boy who loves playing football! When he was a baby I found I slept a lot when he did, which did make it easier. Just don't put any pressure on yourself to do too much in the day as it will catch up on you later :-). I struggle with my mobility, which makes it hard to join in with him now but I find if I just explain to him that "Mummy's legs don't work very well" he then goes to the next person. I am so glad I have my son as he helps keep me sane! So good luck with it and just take each day as it comes.

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**David:** Which drugs, if any, are available for primary progressive patients?

**Nicki - Lecturer Practitioner in MS:** There is lots and lots of research going on into progressive MS both primary and secondary, but we are awaiting various trials to be reported. There is certainly research going on with cannabis as perhaps a drug that can protect nerves from damage, but this is still in very early stages. The trial is called CUPID if you wanted to look this up - there is quite a bit about it on the internet.

**Liz - MS Nurse:** More info can be found on the CUPID Trial website at - <http://www.pms.ac.uk/cnrg/cupid.php>

**Nicki - Lecturer Practitioner in MS:** Another drug that is being looked at for protecting nerves is lamotrigine. An third drug is called Fampridine SR. But none are prescribable at the moment (same old story as Andy said, everything takes a while)

**Liz - MS Nurse:** There is more information about the processes involved in researching treatments in the Research section of the MS Trust website

**Nicki - Lecturer Practitioner in MS:** The MS Society run a yearly conference just for people with primary progressive MS. I spoke at it a couple of weekends ago so it won't be for a while, but worth looking out for next year?

**Simon - MS Trust:** We are hoping to run a chatroom session on progressive MS later in the year. Keep an eye on [www.mstrust.org.uk/chat](http://www.mstrust.org.uk/chat) for info on this

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**Yvonne:** I am so convinced in the value of earliest possible and continuing use of physiotherapy. I would love to see it brought in as a standard for MS treatment.

It takes a while for the dust to settle after the shock of diagnosis for many of us. If the physios had a chance to explain the physical reasons for the changes that are happening and the importance of keeping moving and balanced in posture, the mind will stay more positive.

**Emma - MS Physio:** The importance of physiotherapy management in MS is certainly included in the NICE guidelines (national guidelines). The aims of early physio is to encourage exercise or an active lifestyle, improve a person's awareness of their own body and provide advice for the management of various symptoms.

**Jill:** Are there any specific things someone with MS should be doing, or is it different for everyone?

**Emma - MS Physio:** There are some general principles that apply to everyone. These are around healthy living and lifestyle in general. In terms of physio input, this will vary from person to person as everyone's needs and symptoms are different.

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**Yvonne:** To quote from a relaxation CD I listen to every night (Dick Sutphen's 'The Temple of Light' - "your mind is god, you can make a heaven of hell or a hell of heaven").

To everyone who joins the forum I would love to pass on that message - don't waste energy on feeling 'why me' or 'who is to blame', rather, 'what can I do to help myself' and 'what can I do to help others to help me'

**Alan:** Yvonne's right - staying positive is important, but often very hard to achieve. Being negative is easy but feeds off itself.

**Julie - Jooly's Joint:** My favourite book is 'Happiness Now' by Robert Holden. I agree, a diagnosis of MS isn't so much an end as a beginning. As those of us with MS who have a dark sense of humour say 'MS isn't a death sentence, it's a life sentence'. Which is very true, it is.

I see my health as an extension of my personality (to a degree). Although I believe that ultimately I have little control over the course of my MS, I have found some peace with it in deciding not to be afraid of something that is just another part of me. After you've had MS a while you may find a way of reconciling yourself with it. Life has a habit of going on regardless.

**Alan:** That's true, Julie. It's easy to see MS as a brick wall, when it could be just a diversion to something else. Oops, sound new age-y now :-). And must admit I spent far too long running into the brick wall.

**Julie - Jooly's Joint:** 'Awareness of your own body' - I think that's crucial. At the beginning we can be influenced by caring people around us telling us what we should and shouldn't do. Someone in my life obsessed about me spending too long in bed and would wake me early!. Eventually I came to realise that the person who knew best for me was me (with the support of my healthcare professionals too, of course).

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**DavidB:** My balance is suspect to say the least but I do manage to walk OK (most of the time). I've been told that improving my posture will help with this. It's pretty terrible so anyone have any tips on improving it?

**George - shift.ms:** My posture is/was not the best either. I have felt pilates has really helped

**Emma - MS Physio:** Balance difficulty is a common problem which affects so many people I see. Balance is quite a complex thing with many things affecting it. The angle that I take on it is that if you challenge your balance, it should improve to a certain extent.

If you get in touch with your local physiotherapy department and they should be able to provide you with advice about your posture and balance. You should be able to access this service through you GP

**Liz - MS Nurse:** We have recognised the value of exercise and physiotherapy and as such I refer all newly diagnosed people to Emma for at least an initial assessment and advice provision. However, we appreciate that services around the UK differ significantly and this is not possible in all areas.

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**Andy:** Does anyone have any details on the latest with stem cell replacement?

**Simon - MS Trust:** There are a number of trials going on in various places. One in Bristol is looking at treating people with cells derived from their own tissue (bone marrow I think). Only a pilot study with six people so far, but one of the first trials in humans. The story was covered by the local BBC news and you can see the report in the link from this news story

There is also work about to start in Cambridge that will be looking at using stem cells to repair damage to the optic nerve

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**Sally:** I'm 25, have relapsing-remitting MS and I am fine with coping with MS itself, it's work that is my problem! I have a very positive attitude to the disease - but its making it very difficult to find a job. I seem to be ineligible for any benefits even though it's the symptoms and the fatigue that limits me. Any advice about jobs and work would be very gratefully received!

**Liz - MS Nurse:** Most Job Centres have Disability Employment Advisors although this role within many areas is currently undergoing some changes. They are often the best people to advise on job and career issues. Both the MS Trust and MS Society have excellent publications with much more advice in them about working with MS.

**Nicki - Lecturer Practitioner in MS:** I would recommend a chat with the Disability Employment Advisor at the local job centre. Have you been in touch with one of these people before?

**Sally:** Yes, the DEAs were not at all helpful! This is my main problem - no one is able to offer any constructive advice. One told me to apply for the benefits - they were all denied. Another told me I was best off in the situation I am now in - one I am not very happy with! I feel very stuck.

**Nicki - Lecturer Practitioner in MS:** That's interesting what you say about the DEAs. I certainly find some are great, but I have other patients who say they weren't helpful.

**Sally:** Most advice I have seen regards adapting the job you are already in. I left a postgrad degree because of the MS symptoms and so I have no real work experience. I am starting from scratch which is pretty tricky anyway, but with visual limiations and fatigue issues and not being able to drive I just don't really know where to go!

**Nicki - Lecturer Practitioner in MS:** In Birmingham we have two large disability resource centres that advise people with MS about work issues. Perhaps your MS nurse may point you in the right direction of one of these if there is one in your area?

**Sally:** I'm in Worcestershire, so am able to get to Birmingham quite easily. Would I be able to visit a centre? Is there a weblink?

**Nicki - Lecturer Practitioner in MS:** The best one to access is the Oaktree Lane Centre. If you phone them on 0121 414 1495 they will speak to you. The other one is run by Social Services so will be Birmingham specific. The Oaktree Lane one is not. The two MS nurses in Worcester may know a more local place for you?

**Simon - MS Trust:** A previous chatroom was on employment issues. One of the contributors was a chap from the Working Life Service based in a charity called Neurosupport in Liverpool. You can see the transcript of that chatroom by following the link in the panel at [www.mstrust.org.uk/chat](http://www.mstrust.org.uk/chat), or you can go to the Working Life Service page on the Neurosupport website

**Sally:** Thanks Simon, I'll have a look!

**Louise V:** Citizens Advice helped me with benefits. Disability Living Allowance may be advised

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**Jill:** Hi George - can you tell me more about shift.ms?

**George - shift.ms:** shift.ms aims to support younger people with MS and those closest to them. From my own experiences of dealing with MS (I was diagnosed aged 22 and am now 26) I found existing information and services were not always appropriate to a younger audience. We plan for shift.ms to compliment existing services by creating a community, offering peer led guidance, while also raising awareness and understanding among a younger age group. I'm always looking for input on what people would like on the site! If you email me through [www.shift.ms](http://www.shift.ms) I'll tell you more about it

**Jill:** Thanks George - sounds good.

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**Jill:** It's very easy to find you've switched over from being who you were to being in the 'has MS' box, or 'has disability'. Makes you feel rather ageless and sexless - just an MS stat

**Julie - Jooly's Joint:** I have found re-defining one's self back to being a young woman is an important and very rewarding exercise to undertake. It's important to 'put MS in its place'. It's a part of what you are, not all that you are, etc.

This is where being around other people with MS, 'MS role models' can be so helpful. Finding a blueprint for how to live as a person with MS and as a young woman with all of your aspirations and interests, goals and dreams still intact.

**George - shift.ms:** I agree, it is easy. I agree with Julie - it sounds cheesy but I often need to remind myself that even though MS is a consideration a lot of the time, it shouldn't decide things for me. It's really important to get out there and lead as full a life as possible.

**Julie - Jooly's Joint:** A really useful resource is the BBC Ouch Podcast [www.bbc.co.uk/ouch/podcast](http://www.bbc.co.uk/ouch/podcast). BBC Ouch is for anyone with a disability, impairment or condition and focusses on lifestyle and identity issues. As presenter Mat Fraser says, 'I am whole'. I think this is the core to living a good life with MS or whatever. You are still you, you are whole.

**Jill:** I agree. For a while I turned into 'the patient'. With health services this was understandable (though some were worse than others in this regard). Sadly there was also a period with family and friends where I was 'the patient' too. I guess there were trying to come to terms with it, but it just reinforced the image in my own head. Then I thought, sod it - I'm going dress up and go out and be me

again. I wore myself out and was in bed for two days with fatigue, but I felt I had a toehold on myself again. Since then I've managed to squeeze myself back into my life. Not in one go, but I'm in there again.

**George - shift.ms:** Good to hear it, Jill

**Julie - Jooly's Joint:** It's about management of risk. Arguably, we don't take enough risks enough of the time and the idea of things being dangerous or bad with us get out of proportion with the reality.

Example of risk and MS: the other day I was at a posh awards do. I was going down the stairs at the Grosvenor very gingerly. One of the clients of my company asked if I was ok. I explained that I had MS vertigo and needed to go slow. He said 'but you're wearing high heels!' and I said 'Ah, I am, first and foremost, a woman'. ;-)

**Jill:** Good for you Julie.

**Julie - Jooly's Joint:** In fact I remember talking about high heels at an MS Trust conference a few years ago! I think it's very important to hold on to your sexual identity and personality. They are who you are more than MS is, after all.

Keep your interests up, don't lose a hold on 'yourself'. And don't feel forced to conform to the stereotype of an 'ill person'. That's more likely to make you depressed and feel bad about yourself. My personal motto is 'be fantastic every day'.

Just to put things in context, I also have depressive illness, which is more disabling for me than MS most of the time. This may be why I've put more emphasis on the emotional side of living with MS. For me it's essential to find that balance and to learn to like who I am. I try to be the sort of person I'd like to be friends with, if you see what I mean. Keep your self-esteem high! ;-)

**X:** I remember asking my MS nurse whether MS will make me gay after she told me it affects sexuality! She couldn't stop laughing

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**Nic:** Anyone got thoughts on cannabis? Is it good or bad for MS?

**X:** MS according to my MS consultant is not helped by cannabis I thought that it would help, but he said that it doesn't

**Julie - Jooly's Joint:** Personally I don't use cannabis. This is partly because I don't have symptoms that warrant its use and partly because I have concerns about smoking and the reported negative effects on mental health associated with cannabis use.

But there is now a spray available called Sativex that contains the useful properties of cannabis and I know some people with MS who have found this of great help. I understand that cannabis is of help mostly for people with symptoms such as spasticity.

**X:** What is Sativex?

**Simon - MS Trust:** Sativex is a medicinal form of cannabis. It's given as a mouth spray (you spray under your tongue or into your cheek). It's not licensed in the

UK yet, but can be prescribed on a 'named patient' basis if your GP or consultant think it will be helpful. The MS Trust has a factsheet on Sativex

**X:** My MS consultant said the cannabis is of no help. I am actually on a drug called Tysabri at the moment for people with relapsing/remitting MS with frequent relapses. It's meant to reduce relapses by 75% percent and has resulted in one of the test patients being relapse free for five years so touch wood? I've been on it for 4 months no relapses so far

**Julie - Jooly's Joint:** Cannabis doesn't benefit everyone with MS. I have to say I'm pretty much against 'self medicating' because you need to be aware of your complete health picture. No good making one thing better and another thing worse at the same time. This is why I feel that a good relationship with at least one health care professional is essential because living well with MS is about that partnership.

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**DavidB:** Are there any drugs available on the NHS aimed at progressive MS?

**Liz - MS Nurse:** The majority of management around primary progressive MS is centred around effective symptom management and timely intervention by supporting professionals in cases where this is needed.

**DavidB:** I thought that might be the response. I guess I'll have to wait for science to catch up for something to help with progression. :)

**Liz - MS Nurse:** However, there is a much evidence to demonstrate potential delays in progression over time in the relapsing/remitting type, with the use of the disease modifying drugs.

**Simon - MS Trust:** It's certainly the case that there's no equivalent to the beta interferon drugs for people with progressive MS, but there is certainly work going on in this area - albeit painfully slow from your perspective perhaps.

Open Door had an article on primary progressive MS a few issues back and you can read it at [www.mstrust.org.uk/opendoor](http://www.mstrust.org.uk/opendoor). We're also hoping to have a chatroom on progressive MS later in the year. Watch [www.mstrust.org.uk/chat](http://www.mstrust.org.uk/chat) for more info as plans fall into place.

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**Rachel:** Do you have any advice for a secondary school teacher (diagnosed in NQT year - 1st year of teaching) who loves her job but at times finds it quite difficult, particularly towards the end of a term?

**Liz - MS Nurse:** You don't suggest what the difficulties are but I would guess that fatigue is one of them. If the difficulties are around fatigue then I would suggest addressing these issues wherever possible. Maybe discussing this initially with your MS nurse (if you have one) would be a good place to start. Also, some of the publications mentioned on here about Working with MS and managing Fatigue would be worth a read.

**Rachel:** Yes it is fatigue mainly as it's such an intense job - six weeks holiday but then long terms with a lot of work. I've actually asked to go to four days a week next year. I don't know any other teachers with MS so I don't always know if I'm doing ok if that makes sense!

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**X:** Should a person have it on their CV that he does suffer from MS? I'm scared of discrimination?

**Liz - MS Nurse:** This is a difficult area really with arguments to be made on both sides. I see no reason why it should go on your CV, although declaring it on an application form is a more complex scenario. However, the Disability Discrimination Act states that you do not have to inform an employer generally, although there are exceptions such as when applying to the armed forces.

**Simon - MS Trust:** It's a very understandable concern. However, people with MS are covered by the Disability Discrimination Act from the point of diagnosis - regardless of any actual disability. This means that employers are not able to treat you unfairly just because you have the condition.

**Liz - MS Nurse:** It is important to not lie on an application form though as this can cause problems further on down the line. Additionally, to make things more complicated, it is often of value to declare the illness as soon as possible to ensure that if any support is needed it is readily available from the start. This is an immensely complex area though and there is often no straightforward solution, certainly not one that suits all situations.

**X:** I have done employment law as a module on a post grad course, but I'm just scared of covert discrimination? I have a lot going for me on my CV - I see no reason why having MS which is under control should be hidden?

**Julie - Jooly's Joint:** I agree that covert discrimination is something to feel concerned about. Yes, the DDA exists but do we have to approach every new job with the work about possible legal action on our minds. I know my views on employment are controversial but here they are: if you can hide your MS at interview (ie if your symptoms aren't obvious) and can get through the probationary period, then I'm against mentioning the MS. Once you are confirmed in post, then mention it.

And those of us who are in work and are open about it have got to try to represent the realistic and positive idea of what people with MS are like as employees, as this will eventually become the understood 'norm' among employers, hence people with MS won't have to lie at interviews.

The trouble with the DDA and work is that all it serves to do (in my opinion) is strengthen the idea that people with MS and employment are bad news. It's all negative not positive. I wish it were not so, but I'm afraid this is the reality. Of course, if your symptoms are evident, that's different and if you need specific adaptations at work then you must ask for them. I'm just referring to those of us with remissions.

**X:** I agree with you. I have just spoken to a recruiter he said you should just disclose it at interview

**Julie - Jooly's Joint:** Of course, I'm a special case, in my work, having MS is a positive advantage! (I'm a disability rights campaigner, amongst other things) ;-)

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**Louise V:** Afternoon everyone, good job I'm not shy. I have been asked about my bladder, taught to self catheterise, all about bowel problems, my sex drive! Crikey!

**Alan:** That must have been one hell of a first date :)

**Louise V:** Only doctors, nurses and physios. No first dates in nearly eight years. I split from boyfriend before Christmas and I'm not looking yet. My confidence is at all time low! I found leaving my job was soul destroying. I had therapy for two years. I came to terms with other things more easily (sort of!). My ex didn't. He could not handle the progression of it all

**Julie - Jooly's Joint:** I'm so sorry to hear that Louise.

**Jenny:** Sound familiar, Louise. My boyfriend was terribly understanding at diagnosis, but my first biggie relapse sent him scuttling. I think he was also more freaked than I was when we went to an MS meeting and he saw people in wheelchairs and looking more disabled. Maybe it was better that he bailed out then, but my pride took a kicking

**Julie - Jooly's Joint:** MS is one of many things that can test relationships. Like many people, I found my marriage could not survive, but MS was a part of that not the whole thing. But it's funny how things work out. My current partner, who I met by chance, his best friend has primary progressive MS. You'd think that might put him off (having another MS person in his life) but the opposite is true. He's just one of those people who is totally cool and accepting of others (and no, you can't have him!).

One thing I have learnt is that is probably better to cease with relationships that don't make you feel good about yourself. A person I'm no longer with once told me I'd never survive on my own. Yet here I am, director of a great company, own my own house, etc. etc. Toxic relationships - get rid.

**Jenny:** With a little hindsight, the process was probably quite handy. Cleared out some of the dead wood from my life. People who couldn't cope with me fell away. Hurt like hell at the time, but from the point of view of now it was perhaps for the best

Dead wood is perhaps unfair. He had his own issues to deal with with my MS. But I guess, unlike me, he could walk away and leave it behind.

**Louise V:** Thanks for your support, Jenny. It's getting easier, now that I only have me and the dog to worry about!

**Julie - Jooly's Joint:** Oh and Louise, I'm a big fan of cognitive behavioural therapy (CBT). Good for you for getting therapy, many people are too afraid but it really can help. I hope your experience was a positive one.

Whenever anyone (with MS or not) does something to try to move things on and make them better, I think that's really cool.

**Louise V:** Thanks Julie. The therapy was great help, I'd recommend it.

**Julie - Jooly's Joint:** Glad to hear that, Louise

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**Nadia:** I've been diagnosed with MS for three years. I chose not to tell anyone about it because I'm scared of their reaction - either backing off or treating me like the sick kid in the group. I was OK for most of the time but now find I get very tired when we go out. I have no stamina and start stumbling about like I'm drunk (oh, ok, drunker than I am). Any ideas on what I should do?

**George - shift.ms:** Have you told any of your friends that you have MS?

**Julie - Jooly's Joint:** I know it sounds hard but I would tell people. They've got a right to know who you are and although it will be hard for them (and you at first) that difficult period will pass.

When it comes to personal relationships I always tell people as soon as I can. I've found that if I don't people can feel hurt that I kept something important about me from them and that can be a difficult thing to deal with. When you decide to tell them you can be prepared and have information at hand to help them. You don't have to tell them to their face, you can send them an email or tell them on the phone if that's easier.

**Liz - MS Nurse:** If you look back earlier in the session there has been lots of advice and suggestion given about how to address fatigue management. Do you have an MS nurse? If so they may be able to support you in the process of telling your friends and family about your MS, as I often do with my patients.

**Julie - Jooly's Joint:** Some people will have disappointing reactions. One of my friends stopped seeing me after I told him - he eventually confessed it was because he couldn't handle it. That really is his loss and I feel sorry for him. My other friends are totally cool. Family can be difficult as they can feel a) guilty and b) responsible for making it go away. But life is all about relationships, highs and lows.

**George - shift.ms:** I think it's really important to have someone who knows you personally you can talk to 100% openly. This doesn't need to be your best friend or parent, just someone who you feel comfortable with.

**Julie - Jooly's Joint:** By the way Nadia, you are by no means alone with this. I run an online community of people with MS. About 10 years ago I remember a guy who'd had MS 20 years and experienced a lot of pain. He told me he'd told no-one he had MS, not even his wife! Unsurprisingly, this was causing him a lot of stress. The thing with relationships and friendships is they are about acceptance through good and bad. The experience of MS has taught me the value of good relationships and has also taught me to identify and eliminate 'toxic' relationships. I know I sound a bit hard, but I'm strong when it comes to this stuff (I've had MS 16 years now, this didn't happen over night!). Bad relationships = stress and stress is bad for MS, that's the bottom line.

**Nadia:** I think it's about facing up to something myself. If I don't tell anyone, maybe it's not happening. Once I tell someone else, then it's out there and I don't have any grasp on it anymore. Does that make sense? It took a lot of persuading even to come to this chatroom.

**Liz - MS Nurse:** That does make perfect sense, Nadia, and you are not alone in the way that you are thinking. I know lots of my patients have felt/feel the same.

**Julie - Jooly's Joint:** I totally understand what you're saying, Nadia. I couldn't say 'MS' out loud without crying for the first five years of my diagnosis, so you're doing a lot better than I did. :-) Reaching out for help takes an enormous

amount of courage. Don't underestimate the very big and brave step you've taken and good for you, you for grasping this opportunity today. :-)

**Nadia:** Julie, is the web address in your name the online group? Maybe something a bit anonymous like a web group might be helpful.

**Julie - Jooly's Joint:** Nadia, it's called Jooly's Joint. You will find it at [www.mswebpals.org](http://www.mswebpals.org)

**Nadia:** Thank you. I'll have a look. You've all been very helpful

**Julie - Jooly's Joint:** Small plug: Jooly's Joint has been going for 13 years now. I started it by myself when I was 23. It has around 60,000 members, all people with MS from around the world. I've 'met' tens of thousands of people with MS since starting Jooly's Joint and have met many in person I'm pleased to say. It's all about 'getting your head around' having MS and building friendships with other people with MS. No pressure, just a simple idea.

**Wez:** I understand completely what you are saying. The older you get the more people understand. I find it's just easier to tell people these days. In many ways having MS changed my life for the better. My lifestyle in general got 100% better, plus I get to sleep more - always a winner. If you want to chat and become friends or whatever let me know!

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**Chris:** I don't like to be a party pooper, but my own experience now after 12 years, is that I do wish I had been more honest with myself about the difficulties ahead, that progressive deterioration is the norm. With such honesty, I would have changed my relationships and arranged my activities to do before it's too late.

**Julie - Jooly's Joint:** Ah Chris, hindsight. You couldn't have known - none of us can. When I was 19 I didn't imagine I'd be so much more well at 37. I am the opposite of you. I don't really do regret, but if I did, I'd regret not taking more risks and not pushing it more when I was in my 20s. Then again, maybe my caution has got something to do with my wellness right now. We'll never know.

**Chris:** Thanks Julie. I was thinking a bit more about how I didn't plan ahead. I think such (sometimes brutal) honesty is more conspicuous by its absence, is politically incorrect. There's a risk of thinking of oneself as a victim, but the risks of fantasy I feel are greater.

**John:** I guess MS makes us think about what might happen to us. Living for the day is easy to say but hard to do - especially when young. Something like MS makes you aware that things can change and that you will not always be as young and able as you are now. You can't live your life waiting for the worst case scenario to happen, but it's also perhaps not wise to be blind to the potential consequences of this disease.

**Julie - Jooly's Joint:** I think that mental wellbeing is also extremely important in living with MS. The people with MS whom I know who seem to deal with it best (despite their symptoms) are those who seem to have a really healthy attitude towards MS, relationships and life. I think having positive role models (whatever their age in relation to you) is so helpful. We're very lucky to have the internet. When I was first diagnosed the only option for meeting others with MS was at a support group where most people were in their 40s and much sicker than me. I

know it sounds crass, but if you're going to have MS, 'now' is better than then. We've never had it so good and organisations like the MS Trust are of phenomenal help to those of us trying to live positively with this thing.

**Chris:** That's true. It boils down to taking ownership and responsibility for my life. MS finds us where we are - I react to it following patterns that are already in my psyche.

**Julie - Jooly's Joint:** I think that's a very wise way of looking at it, Chris. A friend of mine once said to me 'how we feel is who we are'. I find that really valuable.

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**Jo:** I'm 19 and was diagnosed in November last year. I was wondering if anyone has felt really undervalued at work since diagnosis. They say they were just looking after me, but it felt like they didn't trust me anymore after I had a relapse with memory problems.

**Julie - Jooly's Joint:** Hi. I'm a bit older than you, but like you I was diagnosed at 19. At that time I was still at university and hadn't started working yet, so didn't go through the experience that you describe. That sounds incredibly frustrating.

**Jo:** Yes it is and I've decided to leave there now and have a fresh start where they won't know the 'old Jo'. But if they would just have given me the chance to prove I was ok again...! If you don't mind me asking, how old are you now? And do you have many symptoms?

**Julie - Jooly's Joint:** Such a tough decision, but I think you're really wise to think about changing jobs. You deserve to be happy in work not made to feel awkward, questioned or analysed (we have doctors for that!) ;-)

I'm ancient, Jo - 37. When I was 19 I never thought I'd work, I was so poorly. Today I'm a company director, I've been to 10 Downing Street and Buckingham Palace and I'm presently writing a new British Standard. I own my own house and life is pretty good. I still have MS and still don't know what tomorrow will bring, but that's life. I've been in remission for some years now. You never know, you never ever know.

What sort of work is it that you do?

**Jo:** Well the thing was it was in accounts so they have to be careful of course. But I used to be so good and do everything and it all just gets taken away... They used to treat me like a child. One time they even wanted me to take a letter to my neurologist! They used to talk to my doctor and my Mum, what do you make of that?

**Julie - Jooly's Joint:** 19 is so young. It's hard for parents and doctors when you're so young to get the balance right but that is bound to change over time simply because you'll get older. I think they naturally want to protect you from the world, and that's a positive thing. but over time they'll come to realise that the person in the driving seat is you. It was like that for me, just as I thought I was finally an adult, MS turned up and suddenly everyone's trying to take over again! But in time it did get better. No-one dares interfere now. ;-)

**Jo:** Ha ha I bet they don't! Yes, I'm in remission at the moment. You wouldn't even know I had it!

**Louise V:** My work was very helpful. My boss's mum has MS. Because of the work I was doing (chef), health and safety decided what I could do and not do - eg non use of stairs but to use the lift, no heavy lifting etc. But I was the only member of staff allowed to carry a mobile phone in case of emergencies. They were quite prepared to make any alterations.

**Julie - Jooly's Joint:** That sounds good, Louise. An enlightened employer. I think it's definitely the case that when an employer has had a positive and realistic experience of MS they are more likely to treat the rest of us in a sensible way in the future. In a way, all those of us with MS who work are 'ambassadors for MS' because employers might treat other people with MS based on their past experience with us. Which is a lot of responsibility on our shoulders, but a huge privilege too if you think about it that way.

**Jo:** I'm not denying work weren't there for me, because they definitely were. But I wanted to be treated like I used to be. I suppose it's hard for them, they have to be careful and everything. Julie, your website is such a good idea! What's a British Standard?

**Julie - Jooly's Joint:** Jo. Cool. Amongst the various things I do to keep boredom at bay (I'm more afraid of being bored than I am of MS!) I'm chair of the British Standards Institution's web accessibility technical committee. I'm responsible for producing new guidance (a British Standard) on how to design websites so that disabled people can use them. There's more about what I've done career-wise here if you are interested: [www.juliehowell.co.uk](http://www.juliehowell.co.uk). I've sort of made a living out of my situation, I make MS work as hard for me as I do for it. ;-)

You will all find that once you have MS some of the people in your lives can be a bit disappointing in what they say and how they behave. But... that is life and that is relationships. On the positive side you could eventually end up with only the really, really cool friends and you'll get really good at spotting potential friends and avoiding people who just drag you down. I have a rule that I won't allow any person or situation to drag me down - I worked too hard for too long to let that happen. I kind of owe it to all the cool people and opportunities to keep my head up, I reckon.

**Jo:** I used to let little things get me down, but now I'm like a different person. I don't know if it's the MS or if I've just grown up recently, but I'm just like 'so what, who cares' you know? And I love it! I love the new me! I even wear things I never would have! Yea, OK, so I'm not always happy and when I get knocked back by one too many guys, I cry for a bit. But then I'm ok again! It's their loss!

**Mary:** Good for you, Jo. MS is such a turning point, isn't it? It can be a negative thing with relationship problems, work problems, limitations on how you live the pre-diagnosis life (I tick all of the above). But it's also an excuse to shake everything around and make new choices. I'm sure I'm allowed to be more eccentric now I have MS, and I love that. Loads I don't love too, but hey. It would be great to spend all night in a club again and sleep off the consequences in one go. But it's also cool to be the weird woman with the stick :-)

**Jo:** Well that's the thing, I can actually still spend all night in a club, and not have any consequences, because I'm not allowed to drink a lot at the moment. I know what you mean, for example if it's raining I'll just put my scarf around my head,

and I don't care that I look like an old woman! There was a time I would have never done that, ha ha I bet you're the cool woman with the stick!

**Yvonne:** One of the founding members of our local MS branch has just had her 91st birthday and she has had MS since she was 17! Her favourite message to any one who has MS is, "OK, you have a bad day, then you pick yourself up dust yourself down and start again." She was certainly a guiding light to me when I first moved to the area some 16 years ago.

**Mary:** I've got a few years to go yet to catch her up, but that sounds a good way to approach life (with or without MS)!

**Julie - Jooly's Joint:** That 91 year old lady sounds fantastic. I plan to live that long. The MS Society recently produced some beer mats that I really don't like because they say on them 'I'm not drunk, I have MS'. I want to get t-shirts done that say 'I'm drunk AND I have MS!' I enjoy a cocktail and that ain't gonna change. It's all about getting a measure of what your body can take and being moderate without being miserable.

**Mary:** I'd buy one, Julie. It's acceptance that we need not making allowances.

**Simon - MS Trust:** This week and next is MS Awareness. The aim of the weeks is to try and raise understanding of MS in the general population. Maybe this will help.

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**Pauline:** I did sit in the garden for a while this morning but the wind made me freezing. My hubbie said that even if it was 100 degrees I would complain of the cold. Are others like that?

**Julie - Jooly's Joint:** I'm one of the one's who isn't much affected by temperature. But I do struggle when there's not much sunshine and have found this winter a bit hard. Sunshine is so important for wellbeing, so I'm very glad it's sunny today!

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**Mary:** Emma, were you involved in the Mr Motivator DVD? I've loved that - gentle exercise and no lycra

**Emma - MS Physio:** No I wasn't. It was a physio called Liz Betts. It is a great DVD and I recommend it to many of my patients. Did you notice the number of outfit changes he made! :-)

**Mary:** I assumed he was some sort of chameleon! :-) They should plug him into the mains - he could power Leicester with all that energy

**Jo:** Ha ha, I used to love him on GMTV!

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**Tony:** I suffer with visual problems. I get a little flickering and my vision sometimes is difficult to see and I find it easier to see if I cover one eye! What would be helpful? I also get lower back pain and pain behind the backs of my knees! I have found that ibuprofen gel helps ease pain but is there anything else I can do?

**Nicki - Lecturer Practitioner in MS:** I must admit to not being an expert on eyes. There is always the basic - when did you last see your optician, as the optician may be able to establish if it is MS or not. What you are experiencing is what I have when I am tired - and I don't have MS. As we are all only too aware, everything is often put down to MS when it may well be something else.

If it is MS, then it is important to see if fatigue makes it worse or not. The optician may well be able to give some general advice too.

About his pain, well this certainly sounds like musculoskeletal pain and so seeing a physio is really important to make sure you are not straining your joints too much. You may be hyper extending your knee when you walk and the physio would be able to advise. Heat can help joint pain as it relaxes. Some people use those bean bags that can be heated up in the microwave. Massage can help joint pain too.

**Emma - MS Physio:** In terms of your back pain and knee pain, I suggest you get a referral to see a physiotherapist. There are many different things that can cause back and other joint pain and without doing an assessment, it's impossible to advise. Your physio may give you some stretches for your legs and maybe some exercises to address your back pain. I hope this is helpful.

**Jo:** My first symptom was optic neuritis which is inflammation of the optic nerve. I found that it was a little blurry but mainly blotchy, as if I had been looking at a light. I also found that lights and colours weren't as bright. Luckily I had it in only one eye, but it came back later on in the other eye! They didn't give me anything for it.

**Julie - Jooly's Joint:** I would echo Nicki's advice to Tony. Not all eye problems are necessarily MS-related and it's good to get an optician's opinion. Personally, I get my eyes tested annually (they're precious!).

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**Jo:** It's not because I've got MS that I can't get drunk, it's because I had a fit (due to where the white patches were). So that's another thing I have to tell employers. And also that's why I can't drive. Has anyone else had a fit? I know there not typical of MS.

**Julie - Jooly's Joint:** I do know people with both MS and epilepsy, Jo, yes.

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**Mary:** I have a touch of spasticity in one leg and aching hips (probably as a result). Are there stretches that would help with this? Is there something I should be doing?

**Emma - MS Physio:** It's difficult to give blanket advice. Generally, gentle stretching can help with spasticity and spasms. Again, your local physiotherapists should be able to give you more individual advice and stretches.

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**Gav:** I was just wondering how other people took the news when they were diagnosed? For me it was just good to finally get the diagnosis, as it had been obvious to me for months that I had it.

And how have you been since the diagnosis? I only ask because I only see it from my point of view, which is insanely positive - not necessarily a bad thing, I might add.

**Julie - Jooly's Joint:** Everyone's experience and journey through life is unique, but it is very good to hear that you remain optimistic and positive (and there's absolutely no reason to change that so keep on keeping on!). I was only 19 when I was diagnosed, so for me it was sort of just another new thing. I think it may be harder to be diagnosed later because MS then is to do with loss... if you have to give up driving or your job. Whereas I hadn't really begun my proper adult life so for me personally it was more 'ok, so this is how things are'. I've therefore never really felt 'loss' with my MS - it really has been more about 'so, what shall we do given this is the way things are'.

**Gav:** I know what you mean about the age thing, I was only diagnosed last year (23) and I think young people deal with things a lot better, I know my parents didn't take the news well, took them weeks to come to terms with the news. It has taken some things away from me, like I can't play the sport I love anymore (ultimate Frisbee - the king of all sports!) But I take the attitude that there's no point being upset/depressed about it, it'd not going to change a thing, and it's not going to make me healthy.

**George - shift.ms:** I count myself very fortunate as I was diagnosed within a month of my first symptom (aged 22). It was obviously a massive shock but I think I dealt with it OK. As people keep saying, it's about finding your way of dealing with your MS and staying positive. Some people find this place quite quickly, other not so - I felt talking about it was a big help in me coming to terms with 'my' MS.

**Gav:** I wish I'd been diagnosed within a month. It took them over 18 months from the first (of many) neurological symptoms, and a year since I started seeing my neurologist, but I'm there now at least. I think I dealt with it so well because it was just so obvious to me that I had it (lots of classic symptoms, optic neuritis, balance, numbness) So I had lots of time to prepare myself for the diagnosis. By the time it got round to the diagnosis, I would have been shocked if my neurologist said I didn't have MS

**James:** I was relieved I didn't have a brain tumour. I had an uncle who'd died with a tumour and the tingling, weird sight and dragging leg had all been things he'd had. His wasn't diagnosed until very late, so naturally I was scared. MS isn't the box I'd tick if I had to have anything, but it's far better than what I thought I had

**Jo:** Same here, James. They thought I could have had one of lots of things, and to be honest, MS was the best of all of them!

**Julie - Jooly's Joint:** I know many people with MS who felt relief at finally receiving the diagnosis. However, this has much to do with the length of time it can take to get an MS diagnosis (the need to rule other things out and to record two episodes in different parts of the central nervous system) - I'm not suggesting anyone is pleased that they have MS.

**George - shift.ms:** Same here, brain tumour was the worry so MS had to be good news. a weird set of emotions to say the least!

**DavidB:** Hmm, I thought I had a brain tumour or so something too. :) I guess there really isn't big awareness out there for MS in the general population.

**Simon - MS Trust:** Trying to alter that (if only a little) is the aim of MS Awareness. All the charities are doing something over the next two weeks to try and spread the message about MS.

At the MS Trust we did a small, informal survey of people here in Letchworth. We asked a hundred people "what do the letters M S stand for?" Almost all knew the answer was multiple sclerosis. When asked what multiple sclerosis does, only a third could come up with an answer. There's a long way to go with awareness raising.

**Julie - Jooly's Joint:** Yes, "I've heard of MS but I don't know what it means" is often what non-MSers say to me. However, with the cause and cure of MS not known it's no real surprise people misunderstand it. Plus the great variety in experience. On hearing that I had MS a taxi driver said to me 'You're not in a wheelchair?'. I said 'nope'. He 'corrected' me 'you mean not yet'. MS is quite complex to explain and unfortunately those that do know about MS often have limited knowledge based on their personal experience of someone they knew that had MS (usually someone either 'marvellous' or 'miserable' and not much in between!).

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**Nicki - Lecturer Practitioner in MS:** Emma, how helpful do you find hydrotherapy? I find it really hard to get for people and there is always the fear that it will over heat them

**Emma - MS Physio:** I have found that it varies from person to person. Sometimes we don't know how effective it will be until we try it. We always have an extra person on poolside in case someone struggles in the pool or getting out of the pool. If the pool is too warm, then I have taken people to local swimming pools which tend to be cooler. The water can be a great place to exercise because the fear of falling is eradicated (so long as the person doesn't fear the water!).....

I appreciate that we are quite lucky to have access to the pool. It wasn't until recently that we were able to use it with our patients. Again, access to hydrotherapy will vary from place to place. We are also able to discuss a patient's appropriateness for something like hydro as we are a relatively small service compared to other areas.

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**DavidB:** I've had problems with coordination for a while. Makes things like doing my teeth rather difficult (I have to use an electric toothbrush now). Is there anything that can help improve things? Exercises or something?

**Emma - MS Physio:** Do you have access to physio and occupational therapy services? They would be able to complete a more comprehensive assessment.

**DavidB:** I'm seeing a physiotherapist and OT but I haven't mentioned my problems with coordination to either of them. Maybe I should tell them about it (although, since my memory is terrible as well I may forget!)

**Nicki - Lecturer Practitioner in MS:** Coordination problems can sometimes be helped with medications and it is certainly worth speaking to your neurologist about these. Drugs like propranolol or clonazepam (although this in particular makes you feel very sleepy). However their effects are not always great. The person who may help here is an occupational therapist who would formally assess your hand movement. She may suggest using weights or other ways of stabilising your arms as much as possible and would also be able to advise on particular pieces of equipment which would be useful

**Emma - MS Physio:** From my point of view, I'm never offended if people come to an appointment with a list of questions/points. In fact, this is something I encourage!

So write it down now or stick a reminder on your phone!

**George - shift.ms:** I totally agree with Emma, one of the best bits of advice I've had is to write down any questions (in priority order!) before an appointment. I have enough going on in my head to avoid having to worry about what I'm going to ask as well!

**DavidB:** Thanks for your answers. Making notes of things certainly sounds like a good idea. I often find myself in front of a consultant or similar, they ask me what I need help with and I'm like, erm, I don't remember.

**Nicki - Lecturer Practitioner in MS:** Consultants are great of course, but they do not always enquire if you have a particular problem so if you are not 'prepared' for what you need to ask you will probably leave the hospital feeling disappointed. Lists are great and some people bring those hand held tape recorders with them to record the consultation as it is easy to forget what is being said

**Jo:** Also there is your MS nurse who will answer any questions you might have. What is yours like?

**DavidB:** My MS nurse is really nice. She's the one who suggested an electric toothbrush.

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**Jo:** So where is everyone from (I'm in Exeter) and do you find there are other young people with MS in your area?

**Louise V:** Buckinghamshire

**George - shift.ms:** Leeds. I find here its generally an older age group who attend local support groups...

**James:** I'm in Hertfordshire. I agree that the groups seem to be older. Very nice people, but with a different view of MS to me with my new diagnosis. I tend to use websites for info and have decided not to join the MS club (at least not yet).

**Liz - MS Nurse:** Leeds sounds similar to Bradford, George. The majority of people in Bradford who attend the various support group meetings are generally not in their 20s and 30s. I believe the same can be said for other areas as well. We are currently working on support group relaunch with the hope of attracting some 'new' and younger members.

**Nicki - Lecturer Practitioner in MS:** We have lots of young people with MS here in Birmingham, although I don't think any more than anywhere else.

We also have a hospital called Birmingham Childrens Hospital where a female neurologist who has come over from Toronto works. She has lots of experience diagnosing children over there, so is 'attracting' the very young and is diagnosing them, MS in kids is very rare, but they are coming from far and wide to be seen at this Hospital

**Jo:** It's almost all older people who go to support groups, even though I know there are a lot of younger people with it

**Gav:** I'm starting a group for people with MS this week, and one of the activities we're going to try is kickboxing. Emma's in charge so I better be nice, or she'll beat me up!

**Nicki - Lecturer Practitioner in MS:** Why kick boxing? Sounds like fun

**Emma - MS Physio:** The group we're running is aiming to help people with day-to-day management of their MS. Part of this is to encourage people to start/continue exercising. We will be having 'taster sessions' of various types of exercise including pilates, yoga, tai chi, physio exercises. We thought that kickboxing might appeal to another group of our patients!

**Liz - MS Nurse:** The group is aimed at people who are newly diagnosed. We aim to focus on the 'how' rather than 'what or why'. In other words we are looking at practical advice and support on issues such as fatigue management, work and benefit advice etc. The exercise part of the program will complement the educational part of the sessions and hopefully provide a relaxed and less classroom type atmosphere.

**Louise V:** I go to my local MS therapy centre in Wendover. I receive physio there but they also offer reflexology and hyperbaric oxygen and have loads of really useful contacts. My best friend does tae kwon do. She is a non-MSer. I don't know if this another option for young people with MS.

**Gav:** I like to call my MS 'Monkey Scrotum' after I saw a Family Guy episode. As you can probably tell, I don't take my MS seriously in the slightest

**DavidB:** I remember that Family Guy episode. Heh :)

**Simon - MS Trust:** I think we'll keep it as multiple sclerosis in the name of the charity - the alternative might be off-putting on the collecting tins :-)

**Liz - MS Nurse:** I agree with Simon on this point. I don't want to be known as the Monkey Scrotum Nurse!

**Nicki - Lecturer Practitioner in MS:** Liz, you are a spoilsport!

**Jo:** Change it to More Special!

**Gav:** It's just my little nickname for the wonder that is MS

**Jo:** I want to see that Family Guy episode - does anyone know how I can find it? Also does anyone watch Neighbours? I don't but I know Susan Kennedy has it

**Gav:** I can't remember the episode name but it was about Peter's childhood bully who gets MS. When Chris tells him not to hit him, Peter proclaims "I don't care if he's got monkey scrotum!" made me laugh a lot as I'd only just been diagnosed when I saw it.

**George - shift.ms:** I have watched it recently (only because of the MS storyline!) I think they've done a pretty good job

**James:** As a Wikipedia bore I can tell you the Family Guy episode is called The Tan Aquatic with Steve Zissou (season 5 programme 11)

**Nicki - Lecturer Practitioner in MS:** Well done James! I didn't know Wikipedia was able to tell you information like that!  
Very useful

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**Nicki - Lecturer Practitioner in MS:** In Neighbours it was rather unusual to have optic neuritis in both eyes at the same time though - I thought this was a bit misleading and inaccurate. I only watched the one episode, how is she now?

**George - shift.ms:** She's ok. She has issues with the heat but good old Karl is there to advise her to get in the shade and have lots of rest!

**DavidB:** I've got optic neuritis in both eyes.

**Nicki - Lecturer Practitioner in MS:** It can happen in both eyes of course but what I mean is that at diagnosis it is very rare to have it present in both eyes at the same time. There is no doubt that it can affect one eye and then the other

**Jo:** I had it in both too

**DavidB:** It's progressive in both eyes for me (joy of joys). I get what you're saying though. I doubt it would start off in both eyes.

**Gav:** I've had it in both eyes, not at the same time, but even so, it's horrible, I can't imagine having it in both at the same time. I wasn't that bothered the first

time as I thought it's OK, my other eye is fine, I can still see. Then when I had it in the other eye it was a bit worse as my other eye never fully recovered (ocular atrophy I think) I did get pretty low at that point. Thankfully it appears to be recovering quite nicely now, at least to the point where I can drive

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**Gav:** What do you class as a relapse? Is it still a relapse if it's only very mild? My feet are feeling slightly odd (slight numbness) but it is only slight. I sometimes think of relapses a bit like an earthquake, different strengths, with aftershocks too, this would probably be about a 2.5 on the Richter scale

**Kate - MS Nurse:** A relapse is when new symptoms develop and last for a period of time (more than a day or two), without there being another reason (such as infection). If it's a relapse, it doesn't go away with rest. They can be very mild

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**Gav:** How do they know when you are relapsing/remitting, primary progressive or secondary progressive? How do they define them?

**Nicki - Lecturer Practitioner in MS:** It is hard to put people with MS into three the 'boxes' relapsing/remitting, primary progressive or secondary progressive. It is such a complicated disease and I see patients where I sometimes find it difficult to know what sort of MS they have.

What these terms mean is how the condition is 'behaving' if you like

Primary progressive is probably a little more straightforward as this is MS which shows progression from onset. Most people with primary progressive do not have relapses, although some can.

Relapsing/remitting MS is certainly the type of MS which most people with MS will present with at the beginning.

Some with relapsing/remitting MS find that over a period of time their MS pattern changes and they develop secondary progressive MS.

I think the titles have become a little more important with the disease modifying drugs that can be prescribed now

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**Z:** Hi, I'm 27 and starting to think about a family. I'm getting confusing messages from family (well meaning but possibly not well informed), and I'm not sure what the research means. Fewer relapses in pregnancy sounds good, but more after is a worry. Any thoughts?

**Kate - MS Nurse:** There is lots of evidence about how having a baby affects MS. Yes there is likely to be a lower risk of relapse during the pregnancy, and an increased risk in the first 3-6 months after. But in the biggest study carried out, only 28% of the women had a relapse in the postnatal period, so there's still a good chance that you won't

**Z:** My family has come up with helpful advice that I wouldn't be able to look after the baby due to fatigue (that I have) and numbness (that I no longer have) or other symptoms. I think they are half expecting me to retire to a wheelchair now.

**Kate - MS Nurse:** Lots of people have to contend with negative comments on this subject from family and friends. I always encourage people with MS to carry on with their plans - where there's a will there's a way. I know loads of women with MS who have had children and managed very well. There is help about if you need it. Have you read the MS Trust leaflet on pregnancy and parenthood?

**Z:** No, I've not seen that. My experience has been that family has been very keen to help and haven't let a lack of knowledge get in the way of the advice they give me.

**Liz - MS Nurse:** You highlighted that your family, although very well intentioned may not be as well informed as they could be. As Kate said there are lots of different publications available that will provide them with re-assuring information and change their expectations maybe.

**Kate - MS Nurse:** Have a look at the leaflet - its very good (I did help a bit with writing it!). I'm glad your family are willing to help out. Maybe they would worry less if you show them the facts about pregnancy and MS (eg it's not going to make it worse) and have a plan of how you would tackle problems such as the fatigue?

**Simon - MS Trust:** You can find the pregnancy factsheet here. Kate also wrote an Open Door article for us on the topic.

**Z:** Thanks for this. I'll try them with the information and see what they say. Ultimately it comes down to me and my partner and whether we could cope with not having a child.

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**Jim:** My wife is 31 years old and was diagnosed with an inflamed optical nerve in January 2008. It is still not 100% better and we have had the obvious conversations with the GP and eye doctor about MS.

The thing is, she went to Costa Rica in October 07 and took malaria tablets. This has caused her to have six months (and still ongoing) of anxiety and panic attacks - which she has never experienced before. At the same time, she has been ill with so many different illnesses since then (bronchitis, acute sinusitis, headaches pretty much every day for three to six months and now lots of weird anxiety related symptoms such as muscle ache, spasm, pins and needles).

So it's all linked. She worries that the symptoms are MS related although the doctor has told us that they are not. It's a vicious circle. Andrea is a headstrong person and all this is so unlike her. It breaks my heart to see her like this. She is being positive - yoga, vitamin supplements, acupuncture etc. She works for herself and I really wonder what would have happened had she been employed by someone else as she has had so much time off work.

So, we have decided not to have the MRI etc tests as this could potentially make her anxiety much worse.

Do you have any pointers for us? Are we on the right track and do you have any experiences that we could learn from.

**Julie - Jooly's Joint:** I'm struck by your comment 'We have decided not to have the MRI as this could potentially make her anxiety worse'. It is a tragedy to be

stuck in holding pattern where the better option is to hold on to the fear of what might happen. If she can get an MRI I would encourage her to do so. Taking 'vitamin supplements' isn't necessarily helping.

If she is worried about having an anxiety attack during the MRI then maybe the doctor can give her something for that. When I had a lumbar puncture I had a panic attack - the doctor gave me an injection of some kind of sedative and I proceeded to laugh all the way through it... anxiety or fear of having anxiety shouldn't be allowed to stand in the way of proper diagnosis and proper treatment, in my opinion...

**Liz - MS Nurse:** I'm sorry to hear that you are both having such a terrible time of things. I personally can't recall anyone who has had the anti malaria tablets and associated symptoms so don't really feel able to comment on their effect or connection to the symptoms that your wife may/may not have had since then. As for the MRI scan, I would suggest definitely having this although I appreciate the concerns over the procedure causing more anxiety. However, with the answers that the MRI may provide, more options for support and potential treatment would be offered.

**Julie - Jooly's Joint:** I fully agree, Liz. Avoiding it just likely to cause more anxiety in the long run. Living in fear of fear is no way to live. MS is not desirable but when she has the facts, and with Jim's support, life with MS can be every bit as rewarding.

**James:** As someone with MS and not a medic, I think I'd agree with Julie. Which is worse - worrying what something might be or finding out what it is? I thought I had a brain tumour, so getting a diagnosis with a lifelong but not terminal condition was a great relief.

**Nicki - Lecturer Practitioner in MS:** It all sounds a nightmare at the moment for both Jim and Andrea. Malaria tablets are horrible and the side effects can really affect some!

I think Andrea needs to discuss these feelings with either a counsellor or her MS nurse. Her MS nurse may feel this is outside her area of expertise but would know where to refer her onto for psychological support. Andrea will need to want to do something about what she is experiencing though and it is often difficult to admit that you need specialised help!

She seems to have got into a spiral of feeling anxious and she seems to be losing some of the control she has over her health. Panic attacks are the way she is coping with her health problems at the moment, but these need to be addressed else they can begin to take over your life.

It's also important that Jim acknowledges that this is hard for him too and treats himself gently.

Andrea is doing the right things with complimentary therapies she may also want to look at carrying out regular relaxation, planning enjoyable things to look forward to that are not too stressful, lots of fresh air and so on. These on their own will not take away her feelings, but will help her as she works through this.

But Andrea needs to acknowledge that she may need some help with this, and that is nothing to be ashamed of!

**Julie - Jooly's Joint:** It's really unfortunate with MS that the diagnostic process is (necessarily) stressful and drawn out. Once people have a diagnosis of MS they so often describe relief from being liberated from 'limbo'. I think it's important to remember that as humans we have an incredible capacity to deal with situations once we get the measure of them. I very strongly feel that it's better to know and then your new life with MS (or whatever) can begin. I'm really troubled to hear of someone effectively self medicating with 'vitamin pills' - it's not necessary and sounds like a bit of an emotional crutch. Again, I feel like I'm being harsh, but if Jim can encourage his wife to look this thing in the eye and get an MRI it's got to be better than waking up every day not knowing.

I agree with Nicki that it's a 'whole person' approach. It hammers home the huge value of access to an MS nurse or counsellor who understands chronic long-term conditions like MS.

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**DavidB:** A silly question popped into my head - are there any male MS nurses?

**Liz - MS Nurse:** Yes, David, I know several

**Kate - MS Nurse:** Yes there are some male MS nurses around the country - the MS Trust would be able to tell you if there's one near to you

**DavidB:** Good to hear, thanks, though I'm not seeking one out or anything. x)

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**Jane:** I'm 22. I was diagnosed with MS last year. I've had optic neuritis (now gone) then a severe stiffness in my arm and leg. My biggest problem is that I that I'm a bit of a party animal and take amphetamines (speed) when clubbing (most weekends). It does make my symptoms worse, but am I making the MS worse?

**Kate - MS Nurse:** I don't think there's evidence that amphetamines will make your MS worse, but there is no doubt that symptoms will be harder to manage if you are partying hard and very regularly

**Nicki - Lecturer Practitioner in MS:** I am not aware of any evidence that says amphetamines make MS worse. But as you know they can make your symptoms worse and whilst partying is absolutely not discouraged, its about moderation I suppose - what a boring person I sound! I am trying to say it's about the balance thing. Don't overdo it else there maybe 'payback'

**Liz - MS Nurse:** I'm not aware of any research/evidence to suggest that the amphetamines will be making the MS specifically worse although there are of course the general health concerns and implications of using speed.

**Kate - MS Nurse:** I know it is hard to have MS when you are young, and just want to carry on without it affecting your lifestyle. Do you cope with your symptoms, and manage everything else in your life (work, family etc), as well as partying hard?

**Julie - Jooly's Joint:** Hi Jane. That's a good question. From a non-medical question, I think it's one of those that sort of answers itself, or rather, I think you know the answer already.... it's about choices and moderation. You don't have to have MS to be affected by persistent recreational use of drugs. Will

amphetamines make you worse? Well, if in ten years time you are worse, are you going to blame yourself for how you lived now? It's one of these questions about 'pay off', I think. You have a lifestyle that you love, but what about the affect of what you do today on tomorrow? I think it's a really personal call.

**Jane:** Everyone is being very sensible when I hoped you say 'no - carry on you'll be fine' :-)

**Nicki - Lecturer Practitioner in MS:** Jane, you knew we wouldn't say that. I suppose its about our experience in the MS community. Certainly as MS nurses you build up intuition based on experience that guides a lot of what we say, we base our answers on all the people with MS that we have seen in the past (as well as the science of course)

**Julie - Jooly's Joint:** Yeah, again balance. What if you stopped doing everything today that was 'bad for you'? How would you feel 20 years from now? Would you regret that decision? Thing is you just don't know. What you'll definitely notice in ten years from now is that your body is less forgiving. It'll take you longer to recover from a bender so recreational use of drugs will be less appealing anyway. After all, who wants to feel ill for days on end! It's really a question of moderation. Huge blow outs every weekend are probably a bad idea even if you don't have MS. Moderate use every now and then, listening to your body, giving yourself a break if your body is telling you to... this is possibly the way to look at it. Besides, if this is a big part of your life now, how would you feel about suddenly cutting it out completely? You should never suddenly cut anything out completely unless you have a plan for replacing it (that's how people end up bingeing, which is arguably the worst thing).

**Nicki - Lecturer Practitioner in MS:** Julie is so right of course, its a personal call. Control is really important with any long-term condition. You need to be the one that's in control when living with MS. You have choices all the time and only you know which ones are right for you

**Julie - Jooly's Joint:** No-one can take speed regularly for a long period and be fine, alas! As I say, as you get older your body will stop recovering so easily plus your recreational tastes will naturally change, you'll have different friends and interests, etc. this applies to everyone, not just us with MS. Ultimately, it's your body, it's got to house you for 80ish years. Listening to it is probably a good idea because it is amazing how quick your 20s fly by and suddenly things do slow down. It might sound like a joy-killer, but when you're 35 and in much better health than your non-MS mates, think how you'll enjoy the gloat. ;-)

If it makes you feel encouraged, Jane, I'm 37 and enjoy a Sex and the City lifestyle. I can get away with this now because I took it a little easier in my 20s (and now I have the money to afford the lifestyle I always suspected I deserved!)

**Jane:** Thanks Julie and nurses

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**S:** I was diagnosed back in 2003 but for a while just denied it and just convinced myself that it was an old football injury. I went to live in Leeds and remember being told by some really horrible people, one in particular, "I didn't ask to live with someone who has MS". From this point I was forced to accept it and never again will I go back to the nasty north!

**K:** There are nasty people in the south too! Ditch the people not the geography

**S:** True, I mean no offence to you or any other northerners - it's just that I had the worst time ever when in Leeds!

**Kate - MS Nurse:** That's such a shame, probably the time in your life when you needed good friends.

**K:** If your experience was like mine, probably best to go through the horrible time and come out of it without the people who blame you for getting MS and who see it as their tragedy.

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**Simon - MS Trust:** We've got about ten minutes to go if people have a few last comments or questions

**Vicky:** I really want to go travelling around the world for a bit before I settle down. I was diagnosed two years ago, but apart from a nasty relapse around that time, things have been fine. Is travelling sensible or will hot climates and backpacking cause my MS to flare up? How about jabs - are they OK for an MSer? Would it be easy to get treatment, especially in countries that don't seem to have as much MS? Sorry, question blurt

**Liz - MS Nurse:** Despite the myths not everyone experiences worsening or heightening of their symptoms in hot climates. I would be sensible and look at options around well ventilated/air conditioned accommodation etc and wearing cool clothes, drinking plenty of cold fluids and having those hand held battery operated fans etc, just in case you do struggle with the heat. Also, make sure you have the appropriate travel insurance just in case you need medical input abroad as it does differ from country to country. The MS Trust has information on reputable companies.

As for vaccines, this is an area into which there has not been much research, however, the general advice is that it is much better to have the jab and avoid the disease it is for. Hope this helps. In a nutshell - go for it!

**Vicky:** Thanks Liz, I'll look into those things

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**Simon - MS Trust:** It's seven, so I'm afraid we'll have to call a halt. Thanks to Emma, George, Nicki and Kate, and to Julie and Liz who have put in very long stints today.

And thanks for all the questions and discussion during the day.

Goodnight