



Ask about your medicines

Chatroom

9 November 2005

www.mstrust.org.uk

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9 November 2005 – 10am to 7pm

The experts:

- **Duncan Petty** – *pharmacist (10am – 12.30pm)*
- **Lorraine Lenehan** – *MS specialist nurse (10am – 3pm)*
- **Meera Sharma** – *pharmacist (12noon – 2pm)*
- **Deepak Lodhia** – *pharmacist (2.30pm – 5.30pm)*
- **Emily Harrison** – *MS specialist nurse (2.30pm – 7pm)*
- **Vicki Gutteridge** – *MS specialist nurse (3pm – 7pm)*
- **Michelle Singleton** – *pharmacist (5pm – 7pm)*

This chatroom is an open forum and so the views expressed by participants are not necessarily those of the MS Trust. For further information on topics raised, please contact the Information team at info@mstrust.org.uk

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Simon – MS Trust: Hello Paul, do you have a question for Lorraine or Duncan?

Paul: Hi. Is there anything I can take to stop me feeling so sick and groggy in the morning?

Lorraine - MS nurse: Hi Paul, thank you for your question. Are you taking any regular medication?

Paul: Rebif 44, but I don't think it's that. I think it's just MS morning sickness

Duncan - pharmacist: Fatigue could be caused by a number of things. For example is your sleep very disturbed? Does pain keep you awake?

Lorraine - MS nurse: Paul, I was wondering how your sleep pattern is? Are you experiencing broken sleep?

Paul: Yes, I never sleep all the way through the night. I tend to wake up three or four times. I am not in pain

Duncan - pharmacist: There are a number of medicines that help with fatigue. Amantadine is most commonly recommended....

Lorraine - MS nurse: Are you woken up by the need to use the bathroom or with pain?

Paul: I've no urinary problems

Duncan - pharmacist: For very short-term use 2-4 weeks sleeping tablets may be useful but in the long term they can be addictive.

Lorraine - MS nurse: I'm just trying to establish the cause of broken sleep, are you having difficulty getting to sleep or just waking in the middle of the night?

Paul: I think it's the Rebif that's keeping me awake. Sometimes after injection I'm lying there awake till 4 or 5

Lorraine - MS nurse: Are you experiencing flu like symptoms - general aches and pains after administering Rebif. Do you take Paracetamol / 'Brufen prior to injection?

Paul: Rebif also makes me very thirsty all night. I drink glass after glass.

Duncan - pharmacist: I am not sure about Rebif causing thirst. I will have to look this one up... I have checked this in the manufacturers data sheet (www.medicines.org.uk) and thirst is not listed as a side effect

Paul: That is really strange....

Lorraine - MS nurse: I was just wondering if excessive drinking has been investigated by your GP as this may be related to another medical condition

Paul: It only happens after the injection, but I was wondering that myself. I will bring it up the next time I see him

Lorraine - MS nurse: I was also wondering if it would be worth considering changing your interferon therapy as it appears to be impacting on your quality of life. Reduced sleep may be exacerbating other symptoms.

Kate: I wanted to thank you for help from last chat room. I have seen a neuropsychologist and have new GP. Get sorted what is MS and what is not

Simon - MS Trust: Good news, Kate - at least you know what your dealing with. Do you have a question for Duncan or Lorraine?

Kate: I'm not on any medication. But when I have to say I have MS most professionals seem surprised. Is it not usual not to be on medication when you have MS?

Simon - MS Trust: It depends on how it affects people. For some symptoms, the medication is not necessarily the best or the only approach

Kate: How does one find out whether medication is the best or only approach?

Simon - MS Trust: Kate, what symptoms do you experience?

Kate: Slow thinking, which if I can't rest goes into cotton-wool head, followed by very poor co-ordination, sensory overload from noisy and things moving - going out can be difficult. Usual sensory stuff in hands and feet, can't stand for long. My walking is improving after bad relapse last year. The mobility clinic did great job sorting out simple gadget to stop spasms at night distorting my foot. This has reduced pain at night so I am sleeping better. Also getting some movement back in the foot which is helping walking

Simon - MS Trust: Therapists can do a great deal for people with MS. You mention helping with spasms. An occupational therapist may be able to help with managing fatigue, and this could help other symptoms

Kate: Yes feel better in myself now sleeping better. One bit with the fatigue is I find if I can lie down for 20 minutes when I get the first sign things return to okay. My GP mentioned something about referring me to neurophysiologist but slow thinking had set in so have to ask more next time I see her. I need to get some hearing test done as that might be contributing to some problems.

Lorraine - MS nurse: I would advise that you discuss this with your GP as they will be know about audiometry services locally.

Kate: Yes tests were done ten years ago - before my MS diagnosis. I was put on a waiting list 15 months ago for some more tests for hearing now digital aids are available

Cazza29: About Avonex, Have been on the drug for nearly ten months now. I still get awful side effects. Do they ever go away?

Duncan - pharmacist: What side effects are you getting with your interferon?

Cazza29: I get flu aches, legs go very weak, balance is affected, feel very down. Just totally rotten and this lasts all the next day. Although one positive about the

drugs is that since I have been on them I haven't had a big relapse! I had four relapses last year! Now I just get smaller flare ups - exacerbations - especially at certain times of the month!!!

Duncan - pharmacist: The flu like symptoms with interferon tend to last three to six months but can persist. Has your neurologists suggested a lower dose?

Cazza29: I haven't seen him, but am worried that if I lower the dose, it will be ineffective.

Duncan - pharmacist: I understand your concerns. It might be worth discussing the options with your neurologist.

Lorraine - MS nurse: It is worth discussing side effects with your neurologist or MS nurse as your symptoms appear to be impacting on your quality of life

Cazza29: OK, I will do. Thank you

Cazza29: Can I ask one more thing before I go? Does anyone have any views on women's MS getting worse during or just before a menstrual cycle?

Duncan - pharmacist: Interferon can sometimes cause irregular bleeding and early or late periods

Cazza29: I was thinking about the fact that once a month my MS seems to flare up very badly before my period, walking becomes nearly impossible, balance goes off and end up in bed for a couple of days!

Lorraine - MS nurse: Women do tend to experience an exacerbation on symptoms approximately 2/3 days prior to menstruation and 1-2 days into cycle. Bladder symptoms in particular.

Cazza29: Thank you, Lorraine

Paul: Are there any anti-depressants that don't cause sexual dysfunction?

Duncan - pharmacist: There are two main types of antidepressants. SSRIs eg fluoxetine (prozac) and tricyclics (eg amitriptyline). The SSRI are associated with sexual dysfunction but it is not commonly so with tricyclics. Are you on either of these?

Paul: Well, I'm not on anything at the moment because of side effects. I have been on sertraline but its double trouble down below if you're a man with MS!

Duncan - pharmacist: Sertraline is an SSRI. If you are still suffering from depression then perhaps try discussing a tricyclic option with your GP. However these may other side effects like dry mouth, blurred vision etc

Paul: Yes, you can't win

Duncan - pharmacist: For mild depression non-drug treatments (such as talking therapies) are a better option.

Lorraine - MS nurse: Are you experiencing problems with sexual dysfunction at present?

Paul: I know it's not a forum on personal matters but I've suffered sexual dysfunction for 5 or 6 years

Lorraine - MS nurse: Have you discussed this with your MS nurse or the continence service? Also, have you had the opportunity to see a counsellor or psychologist to discuss?

Paul: It's never spoken about anywhere

Lorraine - MS nurse: Do you have access to an MS nurse or Continence Service, as this should be a vital part of assessment? Do you feel uncomfortable about discussing this face to face?

Paul: I have an MS nurse, but too shy to bring these things up

Lorraine - MS nurse: Have you discussed bladder/bowel function with your MS nurse, as this is often a way to bring up problems with sexual dysfunction. Are you in a relationship at the moment?

Paul: I'm always single because of MS - no point in finding anyone if it doesn't work if you know what I mean

Simon - MS Trust: Sometimes it can be a tricky subject, Paul. We had a chatroom on sexual problems in June 2003. The transcript is on the website at www.mstrust.org.uk/chat

Paul: I will have a read!

Kate: I found it easier to talk with the continence nurse specialist when I had bowel problems

Lorraine - MS nurse: Paul, if you feel to embarrassed to discuss this with nurse/GP you may want to have a look a www.outsiders.org.uk for some useful information and advice

Paul: I will take a look thanks

Lorraine - MS nurse: Perhaps you should contact your MS nurse. She may be able to arrange an earlier appointment. I am concerned that these side effects are really impacting on your quality of life.

Paul: I will discuss it with her. I'm seeing the nurse in January.

Cazza29: One more question about antidepressants. I have been on lustral 50 mg for a year. It has helped me accept my MS, but I am concerned about its long-term use?

Paul: Yes, Cazza, I was on it for a year and came off it because of that

Cazza29: I did try coming off and couldn't stop crying

Duncan - pharmacist: It is not unusual to be on lustral for many years. The important thing is that it is reviewed by your GP annually. The GP may decide with you to continue it at the present dose or perhaps at a lower (maintenance) dose. Side effects are most likely to occur during the first months of use rather than long term. If you and your GP do decide to stop it then this should be done gradually (over a few weeks). However if you find it helpful then remain on it.

Cazza29: OK, I won't worry about it. Thanks

Simon - MS Trust: Hello Mark, do you have a question for Lorraine or Duncan?

Mark: I just wanted to know if there are any other medications for stiffness. I am taking Zanaflex and have tried Baclofen but my leg is stiff

Lorraine - MS nurse: What dose are you taking?

Mark: I'm taking 4mg four times a day

Lorraine - MS nurse: Have you been reviewed by your neurologist recently as there is scope for increasing the dose? Also you may need to be reviewed by the physiotherapist if you have noticed increased stiffness.

Mark: OK, that sound like the next step.

Marcia: I would like to know about control release tizanidine and if it's available here in the UK

Lorraine - MS nurse: I am not aware that tizanidine CR is available at present. It would be very useful, as tizanidine tends to have a short half life.

Duncan - pharmacist: I think that only Zanaflex (tizanidine 2mg and 4mg) tablets are licensed and available in the UK

Marcia: That's a pity. I'm sure a control release would be better overnight

Simon - MS Trust: Marcia, we will have a nurse from the National Hospital in later who has spoken to a spasticity nurse about this. She may have something to add later on

Marcia: One other question I have is do Oxybutynin patches cut down on side effects

Lorraine - MS nurse: I believe that Oxybutynin XL (controlled release Oxybutynin) may help, as it appears to reduced side effects.

Marcia: Are those in tablet form?

Lorraine - MS nurse: They come in tablet form.

Duncan - pharmacist: The patches may possibly have fewer side effects because the medicine is released more slowly. However 25% of people get a

reaction on the patch site and you could still get some of the side effects you'd expect from the tablets

Peter L: Hello. It appears that every medical practice is obsessed with SSRI's for primary progressive MS?

Lorraine - MS nurse: Are you taking an SSRI at present?

Peter L: I'm now on Citalopram after some awful side effects from various others. Simply, is there anything on the list that does reduce constant symptoms of primary progressive MS?

Lorraine - MS nurse: What are your constant symptoms?

Peter L: Dizziness, fading eyesight, double incontinence, fatigue and lack of co-ordination in my left hand side

Lorraine - MS nurse: Do you have access to an MS specialist nurse?

Peter L: She's rung my wife but we haven't met yet in 12 months

Lorraine - MS nurse: Do you know if a referral has been made, as you appear to have a number of symptoms that need to be addressed? Have you had contact with occupational therapy and physiotherapy services? Have problems with incontinence been assessed by urologist/continence service?

Peter L: No, I see a consultant and GP only. I have been referred to physio and do attempt 'home exercises'

Lorraine - MS nurse: Have problems with incontinence been assessed by urologist/continence service?

Peter L: No

Lorraine - MS nurse: You may benefit from advice from an occupational therapist, as they can address difficulties with vision and fatigue management. Are you taking any medication at present?

Peter L: I think stoicism may be best answer...

Lorraine - MS nurse: I think you should contact your GP and request that an urgent referral is made to the MS nurse, as from the symptoms you are describing, you may benefit from a holistic assessment.

Peter L: Thanks, I'll phone him now.

Lorraine - MS nurse: The MS nurse can advise on symptom management, medication review and recommend onward referrals to other therapists/specialities. Glad to hear you are going to make the call.

Mark W: A question on Vitamin D. Many people take 2000iu (winter) 1000iu (summer). Is there any science behind this and any possible side effects?

Duncan - pharmacist: There is evidence that 800IU a day can help prevent fractured bones in people who are house bound and not getting enough sunlight. Your GP can prescribe products like Calcichew D3 forte. Two daily of these contain 800 units

Duncan - pharmacist: People who do get sunlight in the summer produce enough vitamin D to last the winter. Our rotten winters mean that none of us get enough sunlight to produce vitamin D naturally in winter.

Jeff: Is it true that you can overdose on vitamin D?

Duncan - pharmacist: Vitamin D is not considered an overdose risk. Because it is soluble in urine you simply pee it out. Vitamin A is dangerous in large doses. Arctic explorers have died from eating polar bear liver (rich in vitamin A)!!!

Jeff: I'll avoid polar bears then :-)

Duncan - pharmacist: Yes, polar bears look cuddly but are nasty beasts

Mark W: Duncan thanks. Any thoughts on side effects of vitamin D -does it deplete calcium or other elements? Vitamin A is a known problem, so I use cod body oil not cod liver oil for omega 3

Marcia: My GP told me I could get too high a level of vitamin D in my blood, is this so?

Duncan - pharmacist: So long as you take normal therapeutic doses, vitamin D is unlikely to cause long term problems. Vitamin D causes the body to retain calcium and helps bone absorb calcium from blood. If you have rare conditions in which your blood calcium is too high (eg Pagets disease, bone cancer) then vitamin D supplements would need to be avoided.

Jeff: Does this apply with other vitamins? Some you can get in mega doses - is this wise?

Duncan - pharmacist: Vitamin supplements are not really needed by most people in the UK. Vitamin D, as we have discussed, is helpful for older people who are at risk of osteoporosis (bone thinning). Vitamins A, E, K, C and B are not really of any use. Unless you have a condition that reduces absorption from the guts (eg ulcerative colitis or alcohol abuse (for vitamin B). Vitamin C was thought to be helpful in healing wounds but this has been disproven. Unfortunately extra vitamin C does not protect against the common cold.

Jeff: I've not tried it myself but I know people who swear by vitamin B12 for helping with fatigue

Duncan - pharmacist: Vitamin B12 is an interesting question. People with MS often have a vitamin B12 deficiency. Vitamin B12 helps in making myelin (part of nerve cells). Theoretically vitamin B12 may be of benefit but to my knowledge there have been no clinical trials to test this so the answer is unknown. Having said that it is very easy for your GP or practice nurse to check your vitamin B12 levels. If you are deficient then the treatment is a three monthly injection. Vitamin B12 injections in people with a deficiency are not normally associated with serious side effects.

Steve M: I have B12 injections every 18 months or so and I take Provigil (modafinil). These seem to help greatly with my fatigue

Duncan - pharmacist: Lorraine, can you add to the debate about vitamin B12. Is the theory that you need a normal blood level or is it very large blood levels that could benefit?

Lorraine - MS nurse: The only research that I am aware of concerning B12 was approximately 10-15 years ago. It's not a strong evidence base.

Dice: Vitamin B12, that's the ticket! It gives me energy and helps me think clearly!

Lorraine - MS nurse: Hi Dice, people have reported that fatigue levels improve after having B12

Dice: Your doctor has to inject you with it. Those big drug companies would just freak if you found out about vitamin B12 injectable. The solumedral did correct my double vision problem but the vitamin B12 injectable gave me my energy back. Vitamin B12 injections can cause itching, fever, hot flushes and dizziness. Rarely (sorry I don't know the incidence) serious skin reactions and anaphylaxis (allergic reaction on injection).

Chris: I take 1ml of vitamin B12 injected twice a week. No specific aim. Any opinions?

Duncan - pharmacist: I don't think anybody knows what dose of vitamin B12 would be effective. It isn't proven that vitamin B12 is effective except individuals do report a benefit. However two times a week seems a lot usually a three monthly injection is enough to top up one's vitamin B12 levels because it is stored in the liver.

Chris: Any problem with a lot of B12?

Duncan - pharmacist: I don't know if there are any problems with having to much except it is perhaps unnecessary injections and presumably you have to go to the surgery twice a week or a nurse visits you. The three monthly injection is 1mg.

Chris: Sorry, what's relation of 1ml to 1 mg please? My wife or someone else just injects me, no follow-up.

Duncan - pharmacist: Sorry. The dose is 1mg in 1ml (this is a single ampoule). That is 1 milligram (ie the weight of vitamin B12) in 1 millilitre (ie the volume of water it is dissolved in).

Chris: I think I'm challenged numerically, Duncan. I still can't understand how 1ml of B12 injection twice a week relates to three monthly 1mg.

Duncan - pharmacist: The dose is normally 1mg every three months ie four injections per year. If you are having 1mg twice a week you will be getting about 24mg in three months

Chris: Thanks, Duncan. So is a 1 ml injection equal to a 1 mg?

Duncan - pharmacist: Yes that is correct, 1mg equals 1ml.

Adam: What is a good operating level of B12?

Duncan - pharmacist: Sorry I can't remember the normal B12 blood level. Your practice nurse will be able to look it up on the practice computer.

Adam: I have a print out of some bloods my brother had done in June. It says anything over 150ng/l is normal. Sound right? My brother is also Coeliac. I believe Coeliac's and MSers are known to have low B12, but my brother's level in June was 825 ng/l. Does this sound normal?

Duncan - pharmacist: Over 150ng/l sounds correct. With a level of 825ng/l he will have sufficient B12 to last quite a few months before the next one is due.

Adam: He's never had a B12 Injection, or been offered one. That was his 'natural' level of B12 in June. However, he drinks So Good brand Soya milk quite a lot, which has B12 in it. Could this explain it?

Duncan - pharmacist: Yes most people absorb sufficient B12 through their stomachs from their diet. People who are deficient have normally had their stomachs removed or have a condition called pernicious anaemia (a lack of substance that stops them absorbing B12)

Adam: So, in theory, despite the Coeliac and MS, my brother doesn't need B12 injections?

Adam: He also has a gastro problem called gastroparesis (plus Raynaud's, hiatus hernia, possible IBS), so I was curious as to how his B12 level could be quite high? He is 23 years old

Duncan - pharmacist: The conditions you describe would not affect vitamin B12 absorption. The B12 level he has is not high, it is normal. It is only below 150 that anaemia develops.

Steve M: I have a friend who suffers with vertigo/dizziness and nystagmus. What medication would you recommend, as the medical profession seem to have written her off

Lorraine - MS nurse: Do you know if your friend has tried medication in the past for these symptoms?

Steve M: Unsure what medications she has taken or tried and I'm unable to contact her at present. She has tried most if not all registered drugs for the vertigo! For nystagmus she has tried steroids to no avail. She has primary progressive MS if this helps

Lorraine - MS nurse: Does your friend have a longstanding history of vertigo/dizziness - is this associated with nausea? I am just wondering if she was assessed by a physiotherapist, as they often hold vestibular sessions and exercises called Cooksey-Cawthorne, which help with vertigo.

Steve M: I believe she has suffered for over a year but has had her diagnosis for four years?

Steve M: Is osteoporosis in any way linked with MS? I suffer with this at 44 and have had two hip replacements the last of which was three weeks ago.

Duncan - pharmacist: Osteoporosis is not associated with MS per se, but it is associated with a number of risk factors including being immobile, lack of sunlight, a diet deficient in vitamin D and smoking. In women it occurs after the menopause when their blood oestrogen levels drop.

Lorraine - MS nurse: Have you had steroid therapy in the past

Steve M: I have had steroids orally twice over the last six years or so. Once was for nystagmus, which it cleared up. I can't remember the other occasion. I am not immobile and am able to walk without aid much of the time, except now obviously.

Adam: Can I ask a question about the disease modifying drugs please?

Simon - MS Trust: Ask away, Adam

Adam: My brother has MS. He has been offered disease modifying drugs. They have said recent research shows Rebif and Copaxone to be the most effective generally. Is this true?

Steve M: I am on beta interferon, if that helps, and have been for approximately five or six years

Adam: How have you found it?

Steve M: I believe that the beta is helping me. When does it become time to come off as have seen a friend deteriorate rapidly since he was taken off about 18 months ago? I have heard that beta can cause osteoporosis but my neurologist disagrees.

Lorraine - MS nurse: I do not think that osteoporosis is link with long-term use in interferon.

Adam: What are the MS nurse's opinions on the claim re Rebif and Copaxone?

Lorraine - MS nurse: Generally speaking all disease modifying therapies appear to have similar efficacy, ie reduce relapse rate by a third and reduce the severity of relapse. Your brother may want to visit the website www.msdecisions.org.uk. This provides information on all disease modifying therapies and helps people to decide which one will suit their lifestyle.

Adam: My brother's MS nurse and neurologist recommended Rebif or Copaxone based on the latest research in effectiveness in general. Have you heard this?

Chris: I was taking Rebif for seven years. My private neurologist told me to stop as I had become secondary progressive MS, and he said it is only useful if I have relapses, which is uncommon in secondary progressive. However, I restarted Rebif on my own initiative after a few weeks as I felt subjectively worse. That was very recent.

Lorraine - MS nurse: Adam, you may like to log in later as Emily, another MS specialist nurse, may be aware of the research that was mentioned to your brother.

Simon - MS Trust: Emily works in the disease modifying drugs clinic at a London hospital and so will have a better idea of some of these issues

Adam: What are the side effects of disease modifying drugs? Long term I've heard about liver problems, antibodies and even maybe cancer. Any evidence of this?

Lorraine - MS nurse: Neutralising antibodies is hot subject. I suggest your brother discusses this directly with his neurologist. With regards to liver function, this is monitored every three months for first year and then twice yearly.

Adam: Thanks, Lorraine. How about possible cancer due to disease modifying drugs?

Lorraine - MS nurse: To best of my knowledge, I have not heard of any link to cancer.

Adam: OK, thank you Lorraine. Any other known side effects?

Lorraine - MS nurse: Some people report mild increase in spasticity however this appears to be transient.

Adam: I think my brother is scared they will say in 5-10 years, oh the disease modifying drugs have this nasty side effect. How many years have the interferons and Copaxone been looked at in terms of safety?

Lorraine - MS nurse: There is approximately 8-9 years clinical data available on people taking disease modifying drugs with no serious side effects highlighted

Duncan - pharmacist: Simon, Lorraine and everybody who has asked questions - I am logging off now. It has been good, if not a little nerve racking at first!

Adam: Duncan, thank you for answering the questions

Simon - MS Trust: Thanks to Duncan who has now left the room. Meera, who is a pharmacist, has now joined the chatroom.

Bryan: I've been told that there are some drugs you shouldn't take with St John's Wort - is this the case?

Meera - pharmacist: This is true. There are quite a few drugs that interfere with St John's Wort. Did you have any particular drug in mind?

Bryan: I've been told it's bad with heart drugs

Meera - pharmacist: There are one or two types of heart drugs that it interacts with. Is there any medication that you're concerned about?

Bryan: I had heard it affected warfarin. I take a quarter aspirin daily

Meera - pharmacist: Aspirin is not a problem. The warfarin can be a problem with St John's Wort as it can affect your INR value, which is the ability of blood to clot properly

Simon - MS Trust: Hello Jackie

Jackie: Hello everyone. Has anyone asked anything about gabapentin yet?

Lorraine - MS nurse: Hi Jackie. No major discussion about gabapentin as yet. Would you like to ask a question?

Jackie: I am taking 2700mg gabapentin each day. I was wondering if this is 'normal' and whether my neuropathic pain should improve on this dose

Lorraine - MS nurse: How long have you been taking this dose? If recently increased, have you notice an improvement?

Meera - pharmacist: That dose is high. Was it initiated at the hospital? Your pain should have improved with that dose though.

Lorraine - MS nurse: That the dose is high, although I have seen it at this level.

Jackie: I have seen some improvement but also increased numbness

Lorraine - MS nurse: How long are you taking this dose? Was it increased following a sensory relapse or exacerbation of symptoms?

Lorraine - MS nurse: How long ago did you experience this relapse and commence medication? Where are you experiencing the pain? Sorry about all the questions!

Jackie: My GP has also put me on 25mg dosulepin and 25mg thyroxine. I also take fluoxetine. Is this mix (and gabapentin) OK? The pain got a lot worse a week ago. Experiencing it all over but in my spine worst

Lorraine - MS nurse: Could you let me know how long ago you had this relapse? Do you think you are experiencing exacerbation of symptoms at present?

Jackie: I had the relapse a week ago. The pain is usually under control with 1800mg gabapentin, but it got worse

Lorraine - MS nurse: Meera, I just want to confirm for Jackie that it's OK to take Fluoxetine and Dosulepin together.

Meera - pharmacist: That combination is fine and routinely prescribed.

Lorraine - MS nurse: Thanks Meera. Jackie, did your neurologist advise the increase in gabapentin? Have you contacted your MS nurse for review of these new symptoms? Could you describe her symptoms?

Jackie: GP prescribed increased dose. Seeing my MS nurse tomorrow

Lorraine - MS nurse: Please do not worry about the dose it is within safe parameters. Are your symptoms just pain (sensory) or are you experiencing any motor symptoms?

Jackie: Mainly sensory – my motor skills are more 'wobbly'

Lorraine - MS nurse: Do you have any signs of infection, urinary tract infection/chest infection/ wound etc, as infection can exacerbate symptoms and mimic relapse?

Jackie: I don't think so. Nothing obvious anyway

Lorraine - MS nurse: Prudent to rule out any other factors that may change symptoms. Stress can be a major trigger. Your MS nurse knows your history and will be able to advise.

Jackie: Thanks for your advice, Lorraine. What else can I take?

Lorraine - MS nurse: Are you thinking about changing the medication for pain or altered sensations? Other medications that appear to be effective in managing neuropathic pain are amitriptyline or carbamazepine.

Meera - pharmacist: I agree with Lorraine. Best to check with your doctor or consultant if you wish to switch medications.

Jackie: OK thanks Lorraine and Meera. I have to sign out now - bye all

Lorraine - MS nurse: Good luck tomorrow.

Meera - pharmacist: Best of luck, Jackie.

Peter Z: My wife has trigeminal neuralgia. Has tried about 15 different drugs. She is now on 10mg methadone and 75mg amitriptyline / day. Are there any dangerous long-term effects for taking these drugs? The methadone leaflet mentions no side effects. We have noted body weight increase, is this the amitriptyline?

Meera - pharmacist: Hi Peter. The methadone causes problems only when taken over the recommended dose.

Peter Z: Are there any medications that might help trigeminal neuralgia?

Meera - pharmacist: Other medication might be carbamazepine and amitriptyline.

Lorraine - MS nurse: I was wondering if your wife has exhausted all medication.

Peter Z: Currently my wife is taking methadone 10mg and amitriptyline 75mg/day

Meera - pharmacist: If the amitriptyline is not controlling her pain, she should discuss in the first instance with her doctor. Amitriptyline is quite a good option though.

Lorraine - MS nurse: Is your wife finding it difficult to eat and drink due to facial pain? Also I recall you mentioned that she had taken approximately 15 different drugs without effect. It may be worth trying to get assessed by the pain team.

Peter Z: Thanks

Adam: Is weight gain known in amitriptyline? My brother is on this, but for relaxing the muscles etc for his gastro problems

Meera - pharmacist: Amitriptyline does cause some weight gain as a side effect.

Adam: My brother needed to gain weight. Is it 'safe' weight gain?

Meera - pharmacist: Depends on what other drugs are prescribed alongside. I would probably suggest that it has to be in conjunction with a healthy eating plan as well.

Adam: Sorry I came across wrong. He's not taking the amitriptyline for weight gain, but needed to gain weight. He only takes amitriptyline 10mg

Meera - pharmacist: That dose of amitriptyline is quite safe and usual.

Adam: He also takes lustral (Sertraline) 50-75 mg, lanzaprazole 15mg, propranolol 40mg. The propranolol is for gastro problems, not heart issues.

Meera - pharmacist: That is quite a mixture of medication, but the doses are fine and their combination is also OK.

Adam: He is on Propranolol to relax vegas nerve re stomach/gastro issues, lanzaprazole for reflux, lustral re anxiety. Amitriptyline also for gastro issues (relaxing effect etc).

Meera - pharmacist: That sounds correct. Propranolol is used to relax the muscles, which causes fewer gastro-spasms, and lansoprazole reduces the amount of acid produced in the stomach.

Adam: OK, thanks Meera.

Adam: Are there any dangers in taking supplements? I take Evening Primrose Oil, Flax Seed oil, selenium, chelated calcium/zinc/magnesium, vitamin D, multi-vitamins, vitamin C maybe.

Meera - pharmacist: With the medication that you've highlighted, I would get some advice before getting supplements, as they may interfere with the medication in terms of absorption.

Adam: Oh, and ginkgo biloba. Ginkgo definitely helps circulation. I haven't been diagnosed with MS myself.

Meera - pharmacist: That is quite a mixture of supplements. The ones you need to be careful with are calcium, zinc & magnesium, as I mentioned in terms of absorption.

Adam: I don't take any meds at all, so is it safe to take the calcium, zinc & magnesium? I'm vegetarian and have no milk.

Meera - pharmacist: In that case, it is fine to take the supplements. Don't take them at the same time as milk or milk-based products. Leave a time gap of at least two hours either side.

Adam: Does that include things like bread, which have milk in, or soya milk?

Meera - pharmacist: Bread is not a problem. The soya milk needs a time lapse as mentioned above.

Adam: OK, Thanks Meera

Lorraine - MS nurse: Meera, have heard anything about tizanidine controlled release being licensed in the UK? We had an enquiry earlier as it is available in the States.

Meera - pharmacist: Can't see anything about tizanidine CR being licensed here, Lorraine, but it does make sense from a therapeutic point of view, and I would imagine that it will follow suit here in the UK

Garry: MS has resulted in painful spasms, mostly in my legs and when in bed. Baclofen is all I've been offered, but never felt much benefit. I've heard of someone taking Rivotril. Any thoughts?

Meera - pharmacist: Baclofen is the first-line drug of choice in MS. Rivotril is used more other conditions, and I would have thought that it's use would be as an option.

Lorraine - MS nurse: I have seen clonazepam and Rivotril used mainly for nocturnal spasm.

Chris: Yes, Baclofen is funny. I've been prescribed rising amounts for weakening walking, but seen no benefit or difference

Lorraine - MS nurse: What dose are you taking at present, Chris? Has it been prescribed by a neurologist?

Chris: I started at 5mg a day, rose to 45, now 30mg a day. A neurologist prescribed it

Lorraine - MS nurse: Are you taking that in divided doses? Is there a particular time of the day when you experience more spasm?

Chris: No, very unscientific, just now three times a day, but rarely keep to it.

Meera - pharmacist: I would probably suggest that best to take the baclofen regularly as it's effects can then control the symptoms a lot better.

Lorraine - MS nurse: Are you experiencing difficulty with mobility

Chris: Well gradually my walking deteriorates. I notice no difference with baclofen. Does it really induce drowsiness?

Lorraine - MS nurse: People do report drowsiness as a side effect. You may want to consider tizanidine as it claims to reduce spasticity without causing muscle weakness.

Lorraine - MS nurse: If you were to consider changing over it is advised to titrate baclofen and tizanidine. You would need to discuss this with your neurologist.

Meera - pharmacist: I agree with Lorraine. Baclofen needs to be withdrawn gradually.

Chris: Sorry, what does to 'titrate Baclofen' mean?

Lorraine - MS nurse: You must reduce baclofen slowly and introduce tizanidine gradually. This also requires monitoring of liver function for approx six months once on stabilised dose.

Jeff: How is the seriousness or otherwise of a side effect defined? What might seem mild to one person could completely mess up someone else

Meera - pharmacist: I agree, some people will experience side effects of medication at very low doses, while others will be taking the maximum dose and be fine. It's very much an individual tolerance of drugs.

Simon - MS Trust: Deepak, a pharmacist, has also joined the room

Garry: Any advances with Sativex and cannabis? It has a licence in Canada but nothing here as yet?

Meera - pharmacist: Sativex is still under review with the MHRA, so fingers crossed!

Garry: Is the problem with Sativex in the UK political or will it eventually get a licence?

Meera - pharmacist: The info that I've got at present suggests that the issues are more to do with storage and supply legislation, similar to controlled drugs.

Alice - MS Trust: I keep an eye on Sativex for the MS Trust. The problem seems to be both the historical background and also that the trial data produced so far has not convinced the licensing authorities. It probably will get a licence but the MHRA has asked the manufacturers, GW Pharma, to do more trials first.

[since the chatroom, the situation with Sativex has changed – see our Sativex factsheet]

G: Hi. Are there any treatments available for nystagmus that do not have an effect on erectile dysfunction? I have been prescribed pregablin but concerned about side effects

Lorraine - MS nurse: I have seen low dose baclofen being used for nystagmus - this may have less effect on erectile dysfunction.

Meera - pharmacist: Pregablin has side effects as any other drug. Best to try it and see how you get on initially. It is also a fairly new drug, so needs any side effects reported back to your GP, consultant or pharmacist.

Chris: Recently I was given Ritalin 10mg x 2 to replace amantadine, Isn't Ritalin for attention deficit disorder (ADD)?

Lorraine - MS nurse: You are quite right, Chris, Ritalin is used for children with ADD. It was also used by one of the ladies on Desperate Housewives with amazing effect!!

Meera - pharmacist: Ritalin is used for ADD, but in this instance being used as an addition to therapy for controlling symptoms.

Chris: Which symptoms?

Meera - pharmacist: The symptoms are CNS (central nervous system) related. When you were taking amantadine, there must have been certain symptoms?

Chris: No, amantadine is just prescribed liberally to 'relieve fatigue'. Actually, the only fatigue-related symptom I have is frequent intense yawning, not muscle pain. Is this normal?

Deepak - pharmacist: I have come across this in another patient here before

Chris: Any feedback from them?

Deepak - pharmacist: Feedback has always been that they feel the amantadine is not working yet if they miss a dose, they feel the difference.

Chris: Do you mean the yawning comes back or gets worse if they miss an amantadine dose?

Deepak - pharmacist: Timing of doses makes a difference. They had symptoms of fatigue and slight muscle pain

Chris: Same here.

Meera - pharmacist: Those are the symptoms that I have had feedback on as well.

Chris: Deepak, by fatigue do you mean the same kind of intense yawning as me?

Deepak - pharmacist: The fatigue they describe is yawning and dropping off to sleep

Jude: When I suffer from fatigue I just go to sleep without knowing. The first I know is when I wake up

Deepak - pharmacist: This is exactly as they have described to me

Jude: What can I take for pain? I currently take Gabapentin 400mg, but it doesn't always control the pain.

Deepak - pharmacist: What else are you taking?

Lorraine - MS nurse: Are you taking a maximum dose of 400mgs three times per day? Could you describe the pain and location? Have you tried any other medications?

Jude: I also take amantadine hydrochloride 100mg x 2 and amitriptyline 25mg x 3. The gabapentin is x3

Lorraine - MS nurse: Are taking Amitriptyline 25mgs x 3 in one dose at night time or divided doses throughout the day.

Jude: The amitriptyline is 25mg x3 in one dose at night, but I don't sleep well due to the fact I have to go to the toilet so often. Amantadine does not reduce my fatigue nor my muscle pain

Meera - pharmacist: Hi all, as mentioned earlier, amantadine is used as an addition to therapy, so will not control all the fatigue-related symptoms. Lorraine - is this correct from your experience?

Lorraine - MS nurse: Amantadine is used for fatigue. People normally take one in the morning and if taking a second dose no later than midday/1pm as this can cause insomnia. It sounds like broken sleep may be caused by bladder problems. How many times do you go to the toilet overnight?

Chris: Jude, I take Oxybutinin, imipramine and desmotabs together to reduce going to toilet at night.

Meera - pharmacist: That sounds correct as those drugs affect the bladder muscles and would reduce the frequency.

Chris: It's a funny trio, but seems to work. Used to get up four or five times a night, now once.

Jude: I get up at least 4-5 times a night despite using catheters. It was more before starting to use catheters.

Lorraine - MS nurse: Are you under review by the continence team, as getting up 4-5 times per night is distressing and will have a huge impact on your fatigue levels? Have you discussed this with your MS nurse or continence service as you may benefit from trying a drug – DDAVP?

Meera - pharmacist: That is the same drug (desmotabs) mentioned above by Chris

Jude: I haven't spoken to an MS nurse but will now

Lorraine - MS nurse: Nocturia (going to the toilet during the night) can be distressing. I hope that some medication will help and that you will find that fatigue improves

Jude: Can you tell me the name of the drug again please?

Meera - pharmacist: The drug is DDAVP (Desmotabs)

Lorraine - MS nurse: This medication is also available as a nasal spray.

Chris: Yes, Desmotabs can also be taken as a nasal spray. I've found it very helpful. And getting up so often makes you more tired.

Jude: Should I just go to my GP and discuss DDAVP with him?

Deepak - pharmacist: Yes, though this is also worth discussing with your nurse

Emily - MS nurse: I missed some of the correspondence thus far, so sorry if this has been covered. Do you have a local continence nurse you can speak with?

Jude: I tried to speak with continence nurse but that was over two years ago. The MS nurse showed me how to use catheters when I attended hospital for steroid treatment

Emily - MS nurse: Could your MS nurse link you back in with her? She will have more expertise in using DDAVP. Not sure if this is a possibility?

Jude: So it is probably best to speak to her again. I try not to bother my MS nurse, as I feel my symptoms are not as bad as other peoples

Deepak - pharmacist: Jude, you are never bothering the nurses. They are great and always ready to help!

Emily - MS nurse: That is what your we are there for!

Vicki - MS nurse: As nurses we like to deal with little molehills before they become mountains! No problem is too small!

Jude: I have to go now as have to go to dentist! Thank you for advice to the MS nurses and Deepak

Simon - MS Trust: Thanks to Lorraine and Meera who have now left. Emily and Vicki, who are both MS nurses, have now joined the session. Also online is Deepak, who's a pharmacist

Alison: I've been on Modafinil for about 5 wks. I have more energy but was hyper and couldn't sleep. Now I have halved the dose. Less active but still have trouble sleeping. Is there anything I can do to combat this apart from sleeping pills?

Deepak - pharmacist: Can I ask which strength and when do you take the dose?

Alison: One at breakfast and one about four o'clock

Deepak - pharmacist: I have the patient using meditation CDs to help induce sleep at night time

Deepak - pharmacist: Have a word with the GP about taking the 4pm dose earlier. It may be the prolonged effects of the late dose

Lorraine - MS nurse: It is advisable to take the second dose no later than midday/1pm as otherwise this can cause insomnia.

Alison: Does modafinil (or Provigil) react with citalopram and have adverse effects with vitamins? Being on both citalopram and modafinil my mobility worsened in a matter of weeks

Deepak - pharmacist: No interactions listed in the British National Formulary (reference book of drugs)

Adam: Hi Emily. I hope you don't mind, but can I ask you a question on the disease modifying drugs please?

Emily - MS nurse: Sure

Adam: My brother has MS and has recently been offered the disease modifying drugs. The MS nurse and neurologist said, based on latest research, Rebif and Copaxone are shown to be most effective is this true?

Emily - MS nurse: I would have to know what studies they were quoting. It is difficult to compare any of the research trials 'head to head' as they were all set up differently and have different patient cohorts (eg different entry criteria, patients with differing levels of disability etc...). Across the board all the products seem to be as effective as each other. It is very difficult to make a choice. Has your brother looked at www.msdecisions.org.uk - an independent website discussing the different preparations?

Adam: My brother's symptoms started seven years ago with optic neuritis. He was diagnosed 18 months ago. Only now is he having his first 'real' relapse - vision affected a lot in right eye, left leg giving way, balance etc at times. Previously he's had only transient symptoms (l'hermittes, optic neuritis, numbness in arms for maybe 20 minutes). I was wondering how they decide on which treatment based on these symptoms. My brother is 23 and also has gastroparesis, Coeliac's, Raynaud's.

Adam: Yes, have seen the decisions website thanks. Someone I know said they went on Avonex based on it being better for optic neuritis. Is this true? They claim not to have had any optic neuritis problems since. My brother is sensitive to bright lights in the eyes

Emily - MS nurse: It is an unusual situation in the country, where for the first time patients have the ability to choose the preparation they feel will best suit them. At our hospital, if patients fulfil the entry criteria (basically two relapses in two years) they choose. If they can't make the decision then, of course, the consultant will help them come to a joint decision. I suggest he tries to speak with his Dr and MS nurse. In my experience decision is not based on particular symptoms, however, if patients are having frequent, disabling relapses they may want to consider using a higher dose interferon.

Adam: The problem being knowing which one to go on. The info out there is confusing at times. Is it decided on based on symptoms? And of course, aside of

the website you mentioned, information available is produced by those who make the drugs! So bias etc

Emily - MS nurse: I sympathise with you, and appreciate how difficult the decision is to make. In the longer term, difference of the drugs aside, he must make a decision that best suits his lifestyle - is he in work, needing to travel a lot? Or does he have needle phobias?

Adam: The work situation is cloudy at present. He is with them now discussing things. Aside of the balance/left leg occasionally giving way, and the optic problem, he would normally be in work as normal, no other MS problems (yet) pre-this relapse (we hope it's a relapse!). How long are you on the disease modifying drugs? For life?

Emily - MS nurse: At present this is definitely a longer-term treatment option - well until something better comes along that is! Therefore considering the lifestyle impact is really important...

Adam: What are the long-term side effects? I mentioned to Lorraine earlier about liver problems and antibody problems. I had even heard the disease modifying drugs can increase risk of Cancer. Any truth to this?

Emily - MS nurse: The interferons can cause elevations in liver function, therefore we keep a close eye of it, especially in the first year of treatment. At our hospital we see patients regularly in the first year. Therefore if patients are running into problems, we can work together to best manage them. Yes, there is definitely some debate over neutralising antibodies (NABs), and their significance. I think it's a case of being aware that these may exist. However currently there are no facilities in this country to routinely check for them. Therefore if patients are running into problems, decisions about effect would be on clinical grounds. In terms of longer-term side effects we can't really answer that question, because we don't have the answers, although the drugs have been in use since the mid 1990s

Adam: What are the dangers of the NABs?

Emily - MS nurse: NABs are thought to neutralise the effects of the interferons, therefore making them, in theory, ineffective. However, that doesn't mean to say their effect cannot resume at a later date.

Adam: Ok, thanks Emily. I will ask about this with the neurologist. Is this with everyone, or just some patients?

Emily - MS nurse: Not with every patient. For instance, less than 5% of Avonex patients were shown to develop them.

Adam: OK, Thanks Emily. It is confusing, especially as I say with the literature available coming from those who make the drugs!

Simon - MS Trust: The MS Decisions site mentioned earlier is independent and not put together by manufacturers, so there shouldn't be marketing bias

G: Any thoughts on botox for nystagmus?

Emily - MS nurse: Not sure about your question regarding botox and nystagmus

G: Is it used as a treatment?

Emily - MS nurse: Not in my experience. Vicki, do you know?

Vicki - MS nurse: Botox is used for a different problem of the eye (blepharospasm – spasms in the eyelid causing abnormal blinking or a tic) and would not help nystagmus which is due to a problem inside the brain rather than the muscle of the eye

Alasdair: I am prescribed tizanidine to relieve muscle spasms and am supposed to take 12mg a day. I take 4mg three times a day. The recommended dose leaves me feeling drowsy and tired all through the day, so I have reduced my intake to 4mg a day taken before bed. Should I increase the dose to 12mg and accept the drowsiness?

Emily - MS nurse: It is not uncommon for people to feel drowsy with anti-spasmodic medications. Have you tried any other anti-spasmodic medications?

Alasdair: What else is available that might also be useful?

Vicki - MS nurse: Spasm needs managing with a variety of things. Stretching exercises, correct positioning, relaxation, avoiding constipation. Other medication could include dantrolene as an alternative

Emily - MS nurse: If nocturnal spasms are problematic we might recommend clonazepam instead, due to the liver toxicity of tizanidine.

Vicki - MS nurse: Emily is absolutely right, that is another alternative

Emily - MS nurse: You could try speaking with your physio. If you don't have one ask for a referral. They could help you look at your night time leg positioning, as even a small change in this can reduce muscle spasms.

Alasdair: Thanks

Terry: Has anyone discussed zinc deficiency and what to do about it?

Deepak - pharmacist: What would you like to know?

Terry: Well I did a zinc test and was found to be very deficient, so wondered what I should be taking?

Deepak - pharmacist: Very simply, zinc supplements are available but some formulations interfere with the adsorption of other medicines. Without knowing any specifics, I would suggest that you speak to your nurse about getting a supplement that suits your medications. It is available in doses from 2mg to 15mg- but some doses on the retail market are either too low or too high

Vicki - MS nurse: I agree. Ask your MS nurse about supplements because it may be that your whole diet needs to be assessed.

Terry: Thanks. On another tack, someone mentioned "avoiding constipation", is it OK to anticipate this by taking something daily?

Deepak - pharmacist: Yes products such as lactulose can be used daily but you need to know the causes. Eliminating the causes is the best route

Terry: How does one analyse the causes of constipation? Is there some ingredient that should be in every meal?

Deepak - pharmacist: If it is a lack of bulk- eliminate by eating more fibre. Or if it is a dry impacted stool, then you need a little more bulk and more hydration. If it is a very hard impacted stool, then a stimulate laxative would be better. Sometimes it can be caused by medication, and worth discussing with your pharmacist

Terry: I now live in France, and wonder if there are any foodstuffs I should be avoiding or, alternatively, taking daily as a natural precaution

Deepak - pharmacist: Fresh fruits, vegetables and plenty of water. You can take ispagula husk. Red meat has been known to cause problems in quantity. Also large amounts of breads or wheat based products cause problems because they absorb water in the gut

Terry: I am good with the fruit and veg, but bad with the water, as nervous of being caught short - fairly typical I gather

Deepak - pharmacist: Yes, most patients - and myself included - probably don't drink enough water to suit them.

Kevin: Hi. Are there any drugs that can help with a tremor? I have a cousin whose greatest difficulty is the shaking of her arms - this makes eating and looking after herself almost impossible

Emily - MS nurse: There are no drugs specifically for tremor, however, some people have found that other drugs licensed for other conditions sometime help with MS tremor.

Deepak - pharmacist: Do you know what medication she is on?

Kevin: Don't think she's on anything for the tremor. Some medication for pain but not sure what

Deepak - pharmacist: Like Emily stated, there is no specific product for tremor, but there are products her GP can prescribe to help with the tremor due to their added effects

Hazel: How common are the side-effects of amantadine?

Vicki - MS nurse: They are quite common

Emily - MS nurse: Side effects can be common, and patients can be dose sensitive, so it could be while starting at the lowest dose and seeing how it suits you? Have you discussed this with your MS nurse?

Hazel: Not yet, but I'm seeing her next week

Terry: Have you heard of or used Low Dose Naltrexone (LDN) and if so what do you think about it?

Deepak - pharmacist: I have not had any experience of this to date

Simon - MS Trust: Naltrexone is a drug used with people with addictions, though taken at much lower doses for MS. Some people say they have had a very good response to it

Deepak - pharmacist: Yes I have used it with patients with addictions but was not aware of its use outside that regimen, thank you for that!

Vicki - MS nurse: Some of my patients have tried it but not much success with it

Simon - MS Trust: David sent in a comment about LDN. His comment was principally about the availability of a drug that had little commercial appeal and so would not attract research money

Vicki - MS nurse: It is not yet formally studied for MS... yet

Terry: I know that it has not been formally tested, exactly for the reasons you state, not commercially attractive

Vicki - MS nurse: You will need to be aware it affects the pill

Terry: I have been trying it, so far it has certainly diminished the pain I used to get every afternoon, but no progress on energy etc

Mike: Having tried amantadine, modafinil, Prozac, and found absolutely no effect on fatigue, is there anything else out there please?

Deepak - pharmacist: My experience is that each patient is individual and responds to different treatments

Vicki - MS nurse: Sometimes imipramine can be effective. Have you done a fatigue diary?

Emily - MS nurse: Have you seen an occupational therapist to discuss fatigue management?

Mike: Just completed a fatigue management course

Vicki - MS nurse: How was it?

Mike: Useful for those who can re arrange priorities, but not for someone who already is doing that

Simon - MS Trust: Mike, we've done chatrooms on fatigue in the past. You can see transcripts at www.mstrust.org.uk/chat

Emily - MS nurse: Is the fatigue a long standing problem?

Mike: Yes, a long time

Duncan: I would like to ask about the availability of drugs in our area

Emily - MS nurse: Where do you live? I presume you are talking about the availability of disease modifying drugs?

Duncan: I read about lots of treatments being useful for MS sufferers, like statins, beta interferon, compression chamber [hyperbaric oxygen therapy], etc. GPs and specialists alike usually respond very negatively. Typical responses are "Not licensed", "you're not ill enough", "you're too ill to receive this treatment"

Vicki - MS nurse: We try to keep an open mind about what works for each individual person with MS

Duncan: My wife and her fellow MS sufferers feel like they are on the scrap heap. My wife has secondary progressive

Deepak - pharmacist: I am hearing more about GPs using newer treatments all the time. It's very interesting to hear that you have not had the same response

Vicki - MS nurse: I am sad it feels like that, Duncan. What is it that causes those feelings?

Duncan: She attends a physio class weekly and all her fellows in the class feel the same - on the scrap heap. No one seems to be able to suggest any treatment to slow down the condition

Vicki - MS nurse: We desperately need something to impact on the progression of disability. Lots and lots of research going on to find an answer. Alongside medication to slow things down is the need for something to protect the nerves from all the inflammation so they don't get damaged for good

Chris: Hi Duncan, it's very tough psychologically, the gradual deterioration, for both of you. Sometimes accepting it at some level is a kind of progress.

Kate: Perhaps there should be some more research on things that improve quality of life. I have had some very good help from occupational therapists, and one in particular had such a positive but realistic attitude she passed it on to me

Duncan: It is not just us, it is the whole group

Deepak - pharmacist: I see this in a lot of different conditions – not just MS. There is research being done to look for these treatments. The problem is that the testing and licensing take a long time

Bryan: Duncan, I've been there too. Always seems new research is just behind the progress of one's MS. Very easy to take it personally

Duncan: Not personal - a whole group of about 20

Bryan: Quite, but you know what I mean

Vicki - MS nurse: Thank you for that Kate. The power we have inside ourselves can be immense but we need lots of help to find it sometimes!!

Kate: Yes that kind of help makes a big difference. Perhaps the physio could see the belly dancing article in recent newsletter. Don't have a physio to help on that but got a book from the library about belly dancing for fitness - made me start moving bits that had not moved for a long time

Simon - MS Trust: Kate, was that the article on belly dancing in Open Door, our newsletter. See the list of past articles at www.mstrust.org.uk/opendoor

Kate: Yes that was the article

Vicki - MS nurse: There is a lot of research into quality of life and how to be happy despite physical problems. I have just returned from the big European conference on MS and there was a deep sense of respect for the importance of finding some answers for people who are progressing.

Emily - MS nurse: Duncan, I know of a big secondary progressive trial that is due to start in 2006. Dr Kapoor and Prof Thompson, whom I work with, spoke about it at the recent MS Society AGM. I know it's difficult when you're constantly being told there is nothing to suit your particular type of MS, but there are really exciting bits of research underway. This trial will hopefully give us the evidence for a treatment option for patients with secondary progressive MS.

Duncan: Ace! How do you get things moving?

Chris: Way to go with Kapoor! Even if successful would probably take a decade to appear.

Emily - MS nurse: Yes, I agree, but this is not a new drug to the market, so licensing could in theory be quicker?

Chris: Personally I find I need to live in my current reality, to face myself.

Deepak - pharmacist: I believe everyone involved in the research field is pushing time frames for products to market because they all know of the importance to all!

Bryan: Time is relative of course - what seems fast tracking to researchers can seem like no movement at all from the person with MS's point of view

Deepak - pharmacist: Absolutely Bryan, all things are relative!

Vicki - MS nurse: Emily is right. There are trials with established therapies as well as new drugs.

Chris: Neurologists are fundamentally scientists in a competitive field, establishing their reputation, etc. Good stuff, different from what people with MS face daily and the resources we need.

Vicki - MS nurse: Vicki 30% success to one is 70% failure to another!

Simon - MS Trust: I recently heard someone describe the distinction of how people interpret what is an effective treatment. For the person with the condition, effective means 'makes you better'. For the doctor, effective means 'better than placebo'. Sometimes expectations are built up with no regard for this distinction, which can lead to disappointment

Chris: That's a very valid point, Simon. In the meantime, life goes on ... after a fashion.

Vicki - MS nurse: Chris is right. Don't be distracted from making the most of today.

Kate: think part of making the most of today is having the opportunity to grieve the parts of life I've lost

Duncan: Can you tell me more about the secondary progressive trial

Emily - MS nurse: Sure, but only as much as I know! It is using an oral compound called lamotrigine, an anti-epileptic, sodium channel blocker. It is thought to have neuroprotective qualities. Not sure what the entry criteria will be, and don't have any patient info as yet, I suggest you ask your consultant to write to Dr Kapoor.

Chris: Kapoor is working on neuroprotection, trying to protect axons and nerves from attack. This is very different from disease modifying drugs, which aim to reduce attacks. The trial is based in London, starting in January, so get your skates on.

Duncan: If that is successful - ACE - we're in! But will that be available in Worcestershire?

Emily - MS nurse: It will be a London based projects, but as mentioned I know few details, apart from the ones shared. Ask your GP or neurologist to write to Dr Kapoor at the National Hospital For Neurology & Neurosurgery, Queen Square, London.

Chris: I think part of what motivates Kapoor is the pretty limited use of disease modifying drugs. Sobering to think about for me.

Duncan: Thank you. I am worried that some treatment may be suitable but not available because of our postcode. What do Ms sufferers have to loose?

Vicki - MS nurse: Postcode no longer affects treatments that are proven to be beneficial

Duncan: How come Gloucester can prescribe treatments not available in Worcestershire?

Chris: Personally I find the frantic search for conventional or alternative therapies can become torture for me - distracting.

Deepak - pharmacist: I have looked at alternative therapies and research on the internet but have found most sources to be confusing. Simon, do you know of any recommended sites?

Vicki - MS nurse: Vicki there is a strong growing interest in alternative and complimentary therapy amongst conventional doctors. The Prince's Trust has just published an excellent guide. Allen Bowling also has published an excellent book

Simon - MS Trust: Our newsletter Open Door, published today, carries an article by Vicki about complementary medicines. This has a list of useful links at the end. Unfortunately, space meant that we didn't have room for these in the paper version, but the version that appears on our website includes these links

Duncan: We get more help from MS Trust than many local professionals.

Simon - MS Trust: Thank you. We try to give you the evidence and the information you need to allow you to ask the right questions

Chris: I live in Hong Kong, far fewer cases. I often know more about the disease than the 'specialists'. I think I have to find my own approach/combination.

Kate: I have recently changed GP. I think the old one had me on the scrap heap Duncan referred to. Only just seen new one but she listened and talked with me and seems to be looking at things that were ignored before.

Bryan: Kate, that's a good point. Regardless of what's available, the feeling that you are communicating with doctor, nurse, etc rather than just being told stuff is vital

Vicki - MS nurse: Have you found a new positive approach is improving things?

Emily - MS nurse: I'm glad things have started to move forward for you.

Kate: Hard to say, but feeling more optimistic. Had a rough time last year, and could not communicate what was going on with my GP putting it down to mental health problems. The MS Trust chatroom last March gave me info about the MS cognitive stuff I was experiencing which the occupational therapist listened to and then slowly started making the change

Vicki - MS nurse: Good

Kate: I needed the help of PALS (Patient Advice & Liaison Service). My new GP is realistic, not raising false hopes, but I think will make sure things aren't overlooked

Chris: The sense of communication and sharing is a key factor in the success of these 'e-chats'.

Vicki - MS nurse: I know Hong Kong well, Chris. That is a place where there is a mix of east and west. Has being there made you self reliant in managing your MS?

Chris: Interesting question, Vicki. It's much easier to try acupuncture, Chinese herbal approaches etc in Hong Kong. No particular success in my case, I'm afraid, though beneficial for others.

Vicki - MS nurse: A lot of research into TCM (traditional Chinese medicine) going on at the moment.

Chris: In some senses the ignorance about MS in Hong Kong reduces the 'end-of-the-world' stereotyping that seems prevalent sometimes in UK.

Duncan: Yes, there is a lot of misunderstanding about MS. Some people will not shake hands in case they catch it!

Vicki - MS nurse: Duncan, you wouldn't want to shake hands with someone who was that stupid!!!

Duncan: Yet sadly it does happen. Aren't some people sad?

Gilly: My neurologist has put me on Requip for restless legs associated with my MS. It is only licensed for Parkinson's and no one seems sure of optimal dose.

Emily - MS nurse: Sorry I don't have any experience with this drug.

Gilly: It is a new drug for Parkinson's that is similar to sinemet.

Vicki - MS nurse: I don't have experience of Requip either. I suspect it will be a personal dose response that is unique to you keeping it as low as you can with maximum effect. Requip acts on a part of the brain that regulates movement

Gilly: I thought restless legs was not uncommon with MS but nobody seems to know what I am on about. I used to think it was mini spasms.

Duncan: Yes Gilly, My wife gets restless legs and waxy legs - and like you gets treated like a hypochondriac

Vicki - MS nurse: Does she have any medication for her legs?

Duncan: My wife gets no medication for her legs (or anything else related to MS)

Vicki - MS nurse: Is she on any medication at all?

Duncan: She has thyroxin (not MS related) and pain killers for MS

Vicki - MS nurse: It may be that she would benefit from a review for her symptoms. It may help to reduce some of the negative feelings she has as well as make her more comfortable

Eva: Hi. I've been offered mitoxantrone but was told I can only use it safely for a short while. This sounds scary. Any thoughts?

Emily - MS nurse: Hi Eva. One of the side effects is called cardiotoxicity (affecting heart function). Therefore your medical would have a number of different tests performed prior to you starting. These are called ECG, MUGA or ECHO scan, to look at how your heart functions normally. These would be checked again during the treatment I agree it sounds scary, but in my experience it is well tolerated and we have not seen any cases of what you are describing. However, due to the cardiotoxicity, patients are only allowed a certain lifetime (cumulative) amount of mitoxantrone. This is usually given over 6-8 infusions.

Vicki - MS nurse: As Emily says, there is a specific limit to mitoxantrone because of its possible effect on heart function.

Eva: As beta interferon is taken over a long period of time, are there any problems with being on the drug for years?

Vicki - MS nurse: There is long term data on beta interferons that shows they are well tolerated and effective in the long term

Eva: Is there any difference between Copaxone and beta interferon or are they just different words for the same sort of thing?

Vicki - MS nurse: Yes there is a difference in the way they are constructed. But they all do the same job, just in slightly different ways.

Eva: As homoeopathic medicines are such dilute solutions, do they interact with other drugs or can they be considered safe?

Vicki - MS nurse: Any medication is used with caution. They are used effectively by many practitioners but only after careful assessment of all other medication. There is a consultant called Tom Whitmarsh who practices homeopathic medicine in Glasgow, and the Homeopathic Hospital in London

Eva: I know many doctors don't think much of homoeopathy. Do you think there is anything to it or is it just a case of effectiveness by placebo?

Vicki - MS nurse: I am truly not sure about this. There are some good clinic trials to show it has a positive effect. I think we just don't fully understand it (like many other alternative therapies)

Kate: There is an article somewhere on the MS Trust's web site about homeopathy

Simon - MS Trust: Good spot, Kate. Yes, there is an article by Tom Whitmarsh, just mentioned by Vicki, in the list of Open Door articles at www.mstrust.org.uk/opendoor

Adam: Hi Vicki. Do you know of anything/drugs that cannot be taken when on the disease modifying drugs? Thanks

Vicki - MS nurse: The good thing about disease modifying drugs is that they do not affect anything else you may need to take. It is what we call contra-indication in the trade!

Adam: Does this include everything? Excuse me being frank, but does this include cannabis?

Vicki - MS nurse: Yes it does include that. The caution is that cannabis, if misused, can cause problems in its own right

Adam: I appreciate what you are saying, but just to clarify, cannabis and disease modifying drugs - there are no contraindications. Also, when you say problems 'in its own right', may I ask what you mean?

Vicki - MS nurse: Excessive use can lead to psychological, even psychiatric problems. If smoked it increases the chance of lung cancer over and above just ordinary cigarettes. It is the same in relation to cannabis use along any other drug, or on its own. It has risks. And of course it is still illegal in this country. It is the right derivative from the plant that we need to get on the market, not the illegal plant, which is so uncontrolled in terms of quality and dosage

Simon - MS Trust: The therapeutic version of cannabis that has recently been licensed in Canada is delivered as a mouth spray to avoid the problems associated with smoking

Simon - MS Trust: Emily, did you have any contact with people on the trials that took place at the National?

Emily - MS nurse: Not any intensive contact, just the occasional patient in clinic who was participating. Some people found it quite helpful, whereas others didn't.

Vicki - MS nurse: Cannabis is like any drug. About 30% are helped 30% don't notice any change and 30% are made worse. Those are very approximate figures

Kate: Is anything known about why some are helped, some no noticeable difference and some made worse?

Vicki - MS nurse: Not really. It just seems that all the new drugs tend to produce this ratio. Could be very interesting to research why.

Julie: I have used cannabis and it has helped on some levels

Vicki - MS nurse: That's great. How has it helped?

Julie: For one thing, I am able to stretch better when I smoke it. It eases the pain a bit too. The reason I quit smoking it is that it makes me depressed and paranoid

Vicki - MS nurse: Thanks Julie. It confirms what we said earlier.

Adam: I have never heard of cannabis making anyone worse in terms of their MS

Vicki - MS nurse: It can make the person feel generally worse, not the MS specifically.

Adam: I know the big Walton Centre trial in Liverpool found cannabis useful for spasticity, bladder, sleep, pain etc. I know too it is being looked at now in terms of neuroprotection, as touched on by Dr Kapoor and Prof Alan Thompson.

Vicki - MS nurse: It is definitely being looked at in terms of neuroprotection. This is an important area. If we can protect nerves while inflammation is going on, it buys time

Adam: By the way, I'm not condoning or condemning cannabis. I'm just pro-choice, as it does seem to help many

Vicki - MS nurse: The evidence is very good, and we need to push the government into legislation that will allow Sativex and any future derivatives to be available

Adam: Bizarre that only based on the Walton trials Sativex is legal in Canada but not here?! Politics I guess. I think it's about time the government pulled their

finger out and listen to what the patients (for those who want to) and neurologists are saying

Vicki - MS nurse: You are right Adam. It is pure politics.

Michelle - pharmacist: Getting aback to the cannabis trials, I'm not sure if has achieved what they hoped it would in terms of relief of pain

Emily - MS nurse: Trials always have to have a primary outcome. In the cannabis trial the primary outcome was for spasticity, and pain, bladder etc were secondary outcomes.

Vicki - MS nurse: It works well for a significant group of patients and is well tolerated

Adam: Let me say that I am completely unqualified here Marcia, but they are looking in the CUPID trial at the affects of cannabis. After six months is some preliminary trials it was beneficial in progressive MS. However, as I say, these are just trials and I'm just a laymen (at best!)

Vicki - MS nurse: This the one thing that everyone is desperate to find and hence why neuroprotection is also so important. Trials still go on.

Simon - MS Trust: I believe the licensing arrangements in Canada allow drugs onto the market in a probationary sort of way. It still has to be monitored as part of the arrangement. The equivalent arrangements are not used in the UK system

Vicki - MS nurse: Good evening, Marcia

Marcia: Hello. I was asking this morning about control release tizanidine to make nights more comfortable

Vicki - MS nurse: What dose are you on?

Marcia: I am on 24mg per day

Vicki - MS nurse: The maximum dose is 36mg daily. It would be worth talking to your doctor to see about increasing the night time dose. If it is really bad at times 5mg diazepam can help

Marcia: I'm already taking 8mg diaz, 10mg amitriptyline & 15mg tizanidine at night. Why is control release tizanidine unavailable here and available in other countries

Emily - MS nurse: I am not sure.

Simon - MS Trust: it does seem to be the case that new versions of drugs are sometimes launched in one country first and then spread to others. The versions of the beta interferon drugs that could be stored longer at room temperature seemed to appear in North America some months before they came to Europe

Simon - MS Trust: Thanks to Deepak who has now left. His place is taken by Michelle

Julie: What do you guys know about Rebif?

Douglas: Hi - I also wanted to ask about Rebif

Emily - MS nurse: What do you want to know?

Julie: Well I have been taking it for almost a year and it seems on the days that I take my shots, I am very tired and my pain levels increase ten fold and I feel sick

Douglas: That's similar to my question. I was going to say that for me it makes me feel weak and disorientated

Emily - MS nurse: Has it helped to reduce your relapse rate? How are you getting on with it generally?

Julie: I am considering getting off of it

Vicki - MS nurse: Are you increasing your fluids on injection days and taking your regular paracetamol and/or Ibuprofen for 24hrs at least?

Julie: Not sure what paracetamol is. I am always taking ibuprofen - about 14 a day.

Emily - MS nurse: What time are you taking your injection? Are you taking any ibuprofen or paracetamol prior and post injecting?

Julie: I take my shots at night and tend to sleep 15 hours after taking it

Vicki - MS nurse: Have you both had your blood tests recently? Some patients can only tolerate the 22 dose. What dose are you on Julie?

Julie: 44. Just had blood tests a week ago

Vicki - MS nurse: You may need to go back down to 22

Julie: How important are the medications? Can you control this by diet and exercise?

Vicki - MS nurse: They have a different role, but if the quality of your life is bad you may want to discuss with your neurologist switching drugs or having a drug holiday

Emily - MS nurse: The systemic side effects of interferon cause you to experience flu like reactions and raise your core body temperature. This raise in body temperature can cause 'short circuiting' in nerve pathways previously damaged, thus giving rise to your previous symptoms reappearing just transiently following the injections. To combat this you need to take the Ibuprofen and/or paracetamol regularly to combat this change in temperature.

Vicki - MS nurse: People find that after two years on their beta interferons that they are able to cope much better

Julie: I thought after about two months the side effects would go away, but I have found that they are getting worse over time, not better

Vicki - MS nurse: It may be time to discuss with your neurologist. Some of my patients are fine on 22 but cannot tolerate 44

Julie: I am taking part in a two year study here in Minnesota USA, so I don't know if I should continue until the study is over or not

Vicki - MS nurse: The quality of your life is far more important Julie. It may be incorporated into the study. Chat to your prescriber and do you have an MS nurse?

Julie: I am seeing an MS specialist but I don't have an MS nurse or MS doctor at this time. It seems none of my doctors want to address the pain that I live with daily either, which is very frustrating

Vicki - MS nurse: The study team need to know if you are having bad side effects. Sometimes steroids are a possibility for side effects but not without long-term problems

Julie: I did discuss this all with him but he didn't really do anything to address many of the side effects I am dealing with. Why are these medicines so expensive?

Marcia: Is anything available to slow progression in primary progressive MS?

Adam: Bearing in mind the current controversy of sorts, Aimspro is also being targeted at secondary progressive MS and primary progressive MS I believe

Emily - MS nurse: To my knowledge the trials were only for relapsing/remitting MS and primary progressive MS patients.

Marcia: What is Aimspro?

Simon - MS Trust: Aimspro is goat serum. The only completed trial of which I'm aware was specifically for optic neuritis

Vicki - MS nurse: It is a serum taken from goats. It has been used in the USA for HIV/Aids patients in the past

Julie: What do you guys know about Neurontin for pain

Adam: I have heard that gabapentin and even pregabalin (Lyrica) are better than Neurontin. Is this correct?

Michelle - pharmacist: No, they are very similar in their outcome

Emily - MS nurse: Gabapentin and Neurontin are the same thing.

Vicki - MS nurse: Some patients are finding they can get even better effect from pregabalin. They are all the same group of drugs

Julie: And these are suppose to help with the pain? What are the side effects from taking these?

Vicki - MS nurse: These drugs do help with pain. They are well tolerated and side effects include drowsiness, fatigue some dizziness, but this is rare for most

Michelle - pharmacist: There are many, including dry mouth, constipation, dizziness, vomiting, weight gain, oedema, the list is fairly long. These depend on dose

Vicki - MS nurse: Yes that is an important point, Michelle. Increasing very slowly over five days' intervals is important

Douglas: I use HBO (hyperbaric oxygen) weekly as well as taking Rebif. Any thoughts on problems that this may cause - between the two therapies and with any other drugs?

Emily - MS nurse: Some patients find HBO really useful in assisting with their symptoms, particularly bladder dysfunction and fatigue. Whilst some patients can tolerate it, others can't. In my knowledge I don't know of any interaction between the two.

Vicki - MS nurse: That's right, it is a very individual response with each person

Douglas: Thank you all. Goodbye

Julie: May I ask what role you feel diet plays in MS

Emily - MS nurse: Diet is really important, and is the easiest of all the management approaches to implement into daily life.

Vicki - MS nurse: A very important one. There is some evidence to suggest that disease modifying drugs and diet are more effective than disease modifying drugs alone. And in neuronal health and well being as well as in your overall health and well being.

Emily - MS nurse: A well-balanced healthy diet, low in saturated fats, has shown to have an effect on MS, and as Vicki said is important for your overall well being

Adam: Can I ask what you mean by a good diet? Healthy eating or vitamins etc?

Emily - MS nurse: In terms of good diet, I mean a nutritionally balanced healthy diet, low in saturated fats. If you are doing this you will be getting all the required vitamins and nutrients. In terms of vitamin D, this is a fat soluble vitamin, which you get enough of during the summer months to last you during the winter- even if you were never to go outside.

Adam: OK, thanks. I have seen those advocating Cayce, Best Bet, Swank diets etc, as well as vitamin D increase

Adam: At the MS national conference, Raj Kapoor said he didn't know why vitamins etc are classed as alternative as he had seen first hand how vitamin C, vitamin E, selenium (the anti-oxidants) play a role in helping in MS

Vicki - MS nurse: It is important to have the correct diet, but also to enjoy life. Extreme diets are yet to be fully proven to be worth the effort

Emily - MS nurse: There is no scientific evidence to support those diets, and in practical terms very difficult to manage day to day, however some patient do report feeling improved when implementing them.

Adam: I appreciate that. I am not advocating them, was just curious as to what you thought, and going on what I believe Dr Kapoor said re the antioxidants

Michelle - pharmacist: Studies show that a low fat diet benefits patients and showed that deterioration is slower in those with a low fat diet

Denny: I know low fat, etc is the way to go, but I must admit that occasionally I take solace in a bun

Adam: I will have to sign off now. I just wanted to say a very big thank you to you all. Your responses have been appreciated.

Vicki - MS nurse: Good night to you. Nice to chat to you

Julie: Now, one last question, have you heard about Diet Coke and it causing effects that appear as MS

Simon - MS Trust: Is that aspartame, Julie?

Julie: Yes it is, Simon

Vicki - MS nurse: This may relate to the 'Carrie Loder' issue. She drank coke and thought this was part of her wonder cure. It is not. It could be the caffeine and sugar reducing fatigue

Julie: Have you heard about the effects of aspartame and how it can mask as MS?

Simon - MS Trust: I believe there is a theory that the body turn aspartame into formic acid, which can cause all manner of symptoms. Whether this might cause damage other than in industrial quantities of fizzy drinks seems controversial. Some people say it is wise to avoid these drinks, but there seems no solid evidence to substantiate this at the moment

Vicki - MS nurse: I agree, Simon. Moderation in the things you enjoy is fine, but excessive use, which is unproven, is to be avoided

Michelle - pharmacist: Aspartame is also a diuretic

Heather: I would like to know more about the drug I am taking called tizanidine, which I believe is used in epilepsy

Michelle - pharmacist: Tizanidine is a skeletal muscle relaxant which is indicated for use in spasticity associated with multiple sclerosis or spinal cord injury

Heather: Thank you Michelle - does it have any long term side effects and would a different drug have better results

Michelle - pharmacist: Your liver function needs to be tested frequently on tizanidine and keep an eye for unexplained nausea or fatigue

Heather: Fatigue seems to be the main problem at the moment - so would another drug be better for me?

Vicki - MS nurse: It may be that a switch could help as some people can tolerate some drugs better than others

Cass: When I take steroids for relapses, I find my mood gets very odd and elated. Is this normal and can it be avoided?

Vicki - MS nurse: Yes this 'steroid induced high' can occur and people mistake it for the steroid making them feel better than they really are.

Emily - MS nurse: This is something commonly seen following high dose steroids there is nothing to my knowledge to avoid this. Was this a good feeling or something you would want to avoid in the future?

Cass: It feels good at the time, if fragilely so, but annoys the family no end and is not the time to have the credit card in your purse!

Emily - MS nurse: It's never a good time to have the credit card in the purse!!!!

Michelle - pharmacist: Taking steroids and feeling moody is a very common side effect

Katie: Hi, I have just been prescribed clonazepam for ataxia during relapse, does anyone have experience of this drug and whether it helps?

Vicki - MS nurse: Clonazepam can certainly help some patients who have ataxia. This is a very difficult symptom to treat and also needs OT/physio input

Katie: Unsure as to whether it is helping at the moment. Only on a small dosage. Is it advisable to stop taking it to see if it has any effects, or does the effect occur over time?

Vicki - MS nurse: Carry on, and if you are not yet on maximum dose continue slowly and talk to your neurologist/GP about slowly increasing to get a therapeutic effect

Katie: Thanks Vicki, really helpful. I'm seeing my neurologist in two weeks, but do you know if people have experienced any adverse side effects at higher dosages?

Vicki - MS nurse: No. The key is to increase very slowly

Katie: Really want to think about starting a family soon (although would come off the clonazepam). Do you know if folic acid has any effect on MS?

Vicki - MS nurse: I have another mum who has just had her second baby although wheelchair dependent with lots of ataxia. Successful birth, lovely baby. Stop the clonazepam whilst trying and go on Folic acid (that is OK)

Michelle - pharmacist: Folic acid has very little effect on MS but if thinking of a family it could do no harm but have the benefits of taking folic acid for pregnancy

Katie: Vicki / Michelle - thanks very much, good to hear!

Vicki - MS nurse: Good luck with the family

Denny: Hi. My problem is not the drug so much as remembering to take it. I get forgetful when I get tired. I was advised to take Avonex in the evening but if I'm tired, sometimes I find it tricky to remember to do

Vicki - MS nurse: You need to get a wipe board to write on, or you can get a text message to remind you to take your meds

Viv: Hi, my GP prescribed amitriptyline to help with my bladder. Does anybody know anything about this? I did hear that it may make you feel drowsy the next day.

Marcia: I take amitriptyline at night as a muscle relaxant

Vicki - MS nurse: Amitriptyline is a very useful drug we use for lots of things. It is an anti-depressant we use for many symptoms

Viv: I have been told to take one or two at night. At what time would be the best time to take them? They are 10mg

Vicki - MS nurse: You can take two just before you go to bed and also have a warm drink and try to do a relaxation exercise to help body wind down

Michelle - pharmacist: Amitriptyline 10mg, if you take it about 7-8pm, will not make you feel to drowsy he next day. It has a long half life, 36 hours, which mean it will take a long time to clear out of the body

Viv: Do you think that amitriptyline will make me feel drowsy the next day? This is one of the reasons for me not having taken it before now

Emily - MS nurse: Have you any holidays or quite times coming up where you could try and see what the effect is?

Ellie: Does any one know if anything like gabapentin or any other MS type drug can have any bad effect on my heart condition. I had an MI (myocardial infarction) 18 months ago?

Michelle - pharmacist: What are you taking at the moment?

Ellie: Gabapentin, diazepam, beta blockers, anti cholesterol, also thyroxin. Can't remember!

Michelle - pharmacist: All of those especially your anti cholesterol is important to take. They will not have any harmful effect on your MS

Emily - MS nurse: Copaxone, one of the disease modifying drugs, can cause a side effect where some patients describe chest tightness and palpitations. It is harmless, and I have another patient who takes this drug with a heart condition. You would need to discuss this with you neurologist and MS nurse.

Denny: Are beta blockers used in MS? If so, in what way?

Ellie: My MS nurse has just left - she never came near anyway - and neurologist has also drifted off into the wild blue yonder. Can I ask to see a neurologist in another area? This area is hopeless

Emily - MS nurse: It is a shame you have little or no support. I am sorry to hear that. Could you speak with your GP about referring you elsewhere or speak with the neurologist? I'm not sure of your location, but often management is much easier in the local area, especially if you were to have a relapse in the future.

Vicki - MS nurse: I am sorry that you are stranded, Ellie. What part of the country are you?

Ellie: West Sussex.

Emily - MS nurse: I'm sure you are within your rights to request re-referral to another centre. Perhaps if your GP is supportive you could discuss with her/him?

Ellie: I had the best GP in the World, has just been diagnosed with MS and left - so sad

Emily - MS nurse: That is sad. I hope you get someone equally as good/ helpful and supportive.

Ellie: I am moving to East Sussex soon. It looks worse there from what I can see. I think I may ask for a referral to London - if I can find a GP that is. Do they take patients from out of area at the National Hospital?

Michelle - pharmacist: We have patient from our area (Kent) being treated in London hospitals

Emily - MS nurse: Yes, we are a tertiary referral centre. We get patients from all over.

Ellie: Up to last year we had one of the best medical services in the country - money!

Viv: Just thought are there any drugs that you can recommend for concentration? My level of concentration is really bad

Michelle - pharmacist: No, sorry, I do not know of any drugs that could help for concentration

Emily - MS nurse: The MS Trust hosted a chat room last year on cognition and MS. I read the transcript yesterday and it had some good strategies for managing concentration etc.

Simon - MS Trust: You can find the cognition transcript at www.mstrust.org.uk/chat

Vicki - MS nurse: It is one of the most common problems and can be due to lots of different reasons. As Emily says your team should be able to identify the issues and the things that will help

Denny: I've read that ginkgo biloba helps, but haven't tried it myself

Vicki - MS nurse: There are some anecdotal reports that ginkgo biloba helps

Viv: I'm trying ginkgo biloba at the moment. So far not very much improvement

Duncan: Why are many treatments available in one county and not in the next? Perhaps we may have to move house

Simon - MS Trust: Funding to be blunt. Local funders may not support the full range of drugs. There are some things that can help in this. The NICE Guideline and the National Service Framework both set out the level of service that should be available. Both describe how services should be, but both should be being used as benchmarks towards which service providers should be working. If they are not, you are entitled to keep demanding to know why (of PCTs, councillors, MPs, anyone with clout). You can find more info on both in the Policy and Campaigns area of this website

Vicki - MS nurse: Good evening, Kishan

Kishan: Good evening Vicki, how are you?

Vicki - MS nurse: We are good thanks. And you?

Kishan: Living

Vicki - MS nurse: That does not sound too positive?

Kishan: No, life's a bitch. I'm 23 and was told I've got MS in April. I can't walk properly. Any advise on helping me walk better anyone?

Emily - MS nurse: Have you been put in touch with a local MS nurse?

Kishan: Yes

Vicki - MS nurse: It is like falling into a big black hole isn't it? Your MS nurse can shine a bit of a torch for you

Emily - MS nurse: Have you been referred to or are seeing a neuro-physio? It sounds like that might really help?

Kishan: I've got an appointment next week with my neurologist

Emily - MS nurse: Sounds like it's a very timely appointment. Are you receiving any psychological support to help digest and make sense of the diagnosis?

Vicki - MS nurse: Have you contacted your local MS group?

Kishan: Yes I have. I heard yoga is good for you? I just started that and Reiki. Anyone tried those?

Denny: Don't know Reiki, what is that?

Kishan: It's healing hands. I didn't believe in it at first, but when someone did it to me you could feel heat from their hands. I've known people to go India for treatment and to use natural drugs and it has helped them. I may go to give it a try

Simon - MS Trust: Vicki, in your Open Door article you mention Indian Ayurvedic medicine. Do you have any experience of people using that for MS?

Vicki - MS nurse: I haven't any immediate experience from my patients but would be very interested to hear

Kishan: I don't know people with MS, but know people who had TB and cancer and it has helped them. Has anyone got walking problems or had them before? I can't walk on uneven surfaces

Viv: I have trouble walking and do fall over quite a lot

Kishan: Steroids helped me when I was in hospital on the drip. That was in April

Marcia: Physiotherapy can help with walking, Kishan

Kishan: I'm doing that now. I still haven't come to terms with what I have

Denny: That's the big, big battle, Kishan - don't underestimate that

Kishan: I just don't know what to do - my whole life as come to a stand still

Marcia: It takes quite some time to come to terms with MS - hold in there

Kishan: It's a big stab in the heart. One day I was at university, the next I can't walk

Emily - MS nurse: Marcia's right. Accepting and coming to terms with the diagnosis is so individual, but remember there are enormous amounts of helpful and supportive people out there to help you. Use these people as much or as little as you have to.

Kishan: Why am I getting refused benefits?

Simon - MS Trust: Go to your local Citizens Advice Bureau, or MS Society Branch welfare officer and ask them to do a benefit check for you. Either should be able to help you get all the benefits to which you are entitled

Emily - MS nurse: Are you appealing the decision? Did you receive help completing the paperwork? It can be a really complex and frustrating process, which can be helped if you know how to complete the forms correctly. The MS Society just published a really helpful document, detailing advice on how to complete Disability Living Allowance (DLA) forms. Have you seen this?

Kishan: Yes, I have appealed twice already. My co-worker helped me to fill it in. No, I haven't seen the document.

Simon - MS Trust: Have a look at the MS Society website for their leaflet on Disability Living Allowance and help with benefits. Go to www.mssociety.org.uk and then click on the blue Life With MS button

Emily - MS nurse: Sounds like a good idea.

Simon - MS Trust: And good luck.

Kishan: Thank you for your advice and help

Simon - MS Trust: Thanks for all your questions and thanks to Emily, Vicki, Michelle and the previous experts – Duncan, Lorraine, Meera and Deepak - for all their help with this session