



# **Cognition problems**

**problems with memory,  
concentration, attention span,  
visuospatial awareness and mood**

## **Chatroom**

**13 April 2005**

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

## Cognition problems

**13 April 2005 – 10am to 7pm**

The experts:

- **Patrick Carroll** - occupational therapist (10am – 2pm, 5pm – 7pm)
- **Judy Percy** - MS specialist nurse (10am – 3pm)
- **Sandy Burnfield** - psychiatrist with personal experience of MS (2pm – 7pm)
- **Dawn Langdon** - neuro-psychologist (3pm – 7pm)
- **Hugh Rickards** - neuro-psychiatrist (5.30pm – 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](mailto:info@mstrust.org.uk)

---

**Simon – MS Trust:** Hello Alex, do you have a question for Judy?

**Alex:** Hi Judy, I've had diplopia for three months. Will it go away? Can it be permanent?

**Judy - MS nurse:** Hi, Alex. Thank you for your question. Can you let me know if you are newly diagnosed or if this is a new symptom in an established MS history?

**Alex:** I was diagnosed three years ago and have had one episode of double vision before, which cleared up after a month.

**Judy - MS nurse:** Some symptoms are transient. They may go after six months or so. Symptoms may be affected by poor state of general health. Do you have any infection?

**Alex:** It's difficult as I keep hearing 'some' symptoms are transient, some aren't. I want it to go. I've tried steroids to no effect.

**Judy - MS nurse:** It is so difficult in MS to say which symptoms are going to persist with each individual

---

**Simon – MS Trust:** Hello CJ

**CJ:** I've been having relapses every six months roughly. Will this keep happening? I was diagnosed in October 2002

**Judy - MS nurse:** HI, CJ. Sorry to hear that. Are you on any treatment for your MS?

**CJ:** Daily injections of Copaxone. At times my left eye - mainly - will feel like I have a pair of goggles on with water in it.

**Judy - MS nurse:** Copaxone should help the frequency of your relapses. Is your general health good, getting enough sleep?

**CJ:** No, I awake on and off all night

**Judy - MS nurse:** Sleeplessness will not help your MS. Can you get back to your doctor or MS nurse and try to improve this?

---

**Rachel:** Can I ask how to get an assessment on my workstation?

**Patrick - OT:** Rachel, workstation assessment it depends on local service provision. OTs ought to be able to offer some advice, so can physios? Try the Occupational Therapy department. Under health and safety legislation, your employer has a duty to provide a safe environment

**Rachel:** Thanks I will speak to one

**Patrick - OT:** You could also try contacting the Access to Work service via Jobcentre Plus ([www.jobcentreplus.gov.uk](http://www.jobcentreplus.gov.uk)) as they provide grants for equipment to enable someone to remain employed. Companies don't often know about this and when relieved of the cost can be more flexible in their approach

**Rachel:** I will try the website for Jobcentre Plus. Many thanks

**Sara:** I have found cognitive dysfunction to be causing me increasing problems in my work as a law lecturer. Students will ask me to get or do something for them, to which I readily agree but which I have forgotten by the time I reach my staff room (or even the bottom of the stairs to it!). In conjunction with my employer, the Access to Work organisation has funded, among other things, a handheld voice recorder which I carry around in a mobile phone case at all times, so that I can immediately record any requests/information received whilst away from my staff room. This has proved to be an enormous help, and it reduces my anxiety that I might have forgotten something important. Access to Work can be contacted through the Department of Work and Pensions ([www.dwp.gov.uk](http://www.dwp.gov.uk)). It is really worth contacting them if you have not already done so - I was directed to them by my OT. Hope this may be of help to someone.

---

**Ron:** I have a question about mood swings. Is it normal to have mood swings? I have read about two people over the last two weeks who appear to have severe mood swings.

**Judy - MS nurse:** Hi, Ron, is it you yourself, as an MS person, having mood swings

**Ron:** I do not think I have a problem with this, just maybe something that might be headed my way and am a little concerned.

**Alex:** my partner says I do!!

**Ron:** I have MS, but it is not me with the mood swings, it is postings I have read posted by others. They say it makes them very angry

**Judy - MS nurse:** Thanks Ron. Some people do have mood swings - but if you haven't had them so far - great! But if you feel them coming on - get help

**Alex:** Is it the MS, or frustrations of MS that causes 'swings'?

**Judy - MS nurse:** Alex, yes, the frustration of your situation can certainly increase mood swings!

**Ron:** So is it something that might be normal with MS? I certainly get frustrated at not being as able to do simple things that I used to, but have not really had feelings of anger

**Lyn - SLT:** Hello, this is Lyn, a speech and language therapist. Are there any other SLTs here working with cognitive difficulties, or any clients who have been helped by SLT input for cognitive difficulties?

**Simon - MS Trust:** Lyn, I think you're the only SLT here at the moment. Do you see many people with these sorts of problems?

**Lyn - SLT:** Yes, we can help with language processing and memory. It can be useful to see SLT with the person you speak with most. That way the other person can learn to modify their own communication to help you process.

**Dave:** [question sent in advance] I have had MS now for over ten years now and apart from epilepsy, mobility and fatigue my next biggest problem is my memory, is this rapidly going to deteriorate?

This January, I was prescribed with Copaxone, this is after ten years, is a pretty miserable state of affairs, when now at the age of 50 I think of the wasted important part of my life is gone. The things I wish me my wife and kids could be doing no that now I cannot.

Is there any chance that my memory could improve, or are there any ways of developing for myself a better memory?

**Rachel:** I have spoken to two doctors about forgetting things and they just say its stress related!

**Judy - MS nurse:** There are several things you can do to help memory. Keep a diary, write things down, keep to a routine. More to follow!

**Rachel:** Judy, I have started carrying a PDA (personal digital assistant - electronic notebook) to help remember stuff

**Judy - MS nurse:** I am writing a booklet that will have hints in memory etc. Ideas such as

- having a whiteboard or blackboard for general information storage
- using a wrist watch with an alarm
- keeping a notepad and pen by the phone
- making lists before going shopping or starting a job
- maintaining special places for reading glasses, TV controls, car keys etc, so that finding these items becomes routine.

It can help to break down new information into manageable chunks and adapt it into your own words. Try to concentrate on the meaningful, relevant and essential information and to cut out some of the less relevant details. Memory

games or multi-sense input (eg writing down what you have read, or saying things out loud) can be helpful.

**Ron:** I use 'word association' to remember things, especially names and find it quite good

**Lyn - SLT:** Good idea! It is useful to find 'hooks' to hang things on

**Judy - MS nurse:** Hooks are wonderful - especially if you think of outrageous ones! It keeps the imagination going!

**Ron:** What do you mean by 'hooks?'

**Judy - MS nurse:** Hooks are an images you create around what you need to remember. Remember a name by creating something outrageous or funny connected to it!

**Lyn - SLT:** One of my patients remembers my name as it rhymes with the local crematorium!!! It works for him. Other ways are to link someone's name with some obvious feature or because it is the same as someone else you know.

**Patrick - OT:** As regards hooks for memory, there are lots of 'internal' memory aids but you need to remember that trying to hold something in memory takes energy. Most people with memory problems gain from externalising the storage of the information in diaries, notes or recording devices

**Lyn - SLT:** You need to be selective. Do you really need to remember it?

**Ron:** OK thanks

**Jonathon:** My problem is also memory. Shot to pieces and can't work without sticky notes. Any suggestions that don't involve writing anything as fine motor skills have gone as well

**Lyn - SLT:** Sticky notes are great. They can fall off though. Sometimes drawing bigger symbols can be enough to jog your memory. You don't need to write the whole word or even any letters

**Patrick - OT:** How about a digital dictaphone that has voice operation? Where writing or typing is a problem, voice operated computer systems can be used and they'll link with Outlook diaries. Try AbilityNet for advice. The AbilityNet website can be found at [www.abilitynet.org.uk](http://www.abilitynet.org.uk)

**Judy - MS nurse:** A dictaphone is also discrete - you can hide it in a pocket, not so visual!

**Rachel:** I use a PDA with add on large touchpad

**Jeremy:** [question sent in advance] Hello, I am looking for help with my brain functions, I can't seem to sort much out these days, this includes filling in forms from the Incapacity Benefit and DLA, which are now becoming a real problem for me. I don't seem to be able to explain why I am (so I think) disabled. More mentally disabled than physically, or is it that I have just become very lazy and given up? I have relapsing/remitting MS, diagnosed four years ago, and it would seem to me this brain dysfunction has got a lot worse in the past five months since I had a short course of steroids to give me more energy and get up and go. Go down hill I think! I have reported this to my MS nurse and my neurologist last

week and he gave me Selegiline tablets (10mg) once a day at 10am. No change yet. My MS nurse is puzzled by me as so far nothing seems to improve my situation, she said at our last meeting I am "an odd one". I used to be very intelligent and had a responsible job, but now no job and I can't 'get it together' to improve my situation. I did go back to college and passed my computer exam last year, but I can't get it together now. Help! I need, and want to be able to earn some money

**Judy - MS nurse:** Jeremy, you're not lazy. The DLA forms are enough to tax a mastermind! Get help filling them in – MS Society branch welfare officers can help, contact your local citizen's advice bureau ([www.nacab.org.uk](http://www.nacab.org.uk)) or ask the DSS to send someone round. To take an alternative route – try your Access To Work team at your local Jobcentre and have an assessment. They may suggest the kind of work you can do without the stress of going through a degree course.

---

**Alex:** Is it good to alternate 'patching' of eyes?

**Judy - MS nurse:** Yes, patching will help rest your eye and give your brain a rest too - difficult to cope with two images going instead of one!

**Alex:** Do I have to alternate? I'm practically wearing one all the time now, 'pirate' style.

**Judy - MS nurse:** Have you sought help from your neurologist yet - what does he/she suggest?

**Karen:** Hi all. Do you have any tips for me being so tired all the time?

**Rachel:** Karen I find little and often 'naps' work best for me, however you will have to find your own pattern

**Judy - MS nurse:** Hi, Karen. Fatigue is a big problem. There are a multitude of things you can avoid and help to get. Are you in touch with an MS nurse?

**Karen:** No I don't get any help from anyone, only it seems when I have an attack

**Rachel:** Judy, do you know if there is a list of MS nurses?

**Simon – MS Trust:** Rachel, there isn't a published list as different services have different referral criteria. If you are looking for an MS nurse, you can contact us at the MS Trust ([info@mstrust.org.uk](mailto:info@mstrust.org.uk)) and we can find out if there is someone in your area and what you need to do to get in contact (eg who needs to make the referral or if it's open access).

**Karen:** Thanks that would be great

---

**Hazel:** Can anyone provide any clues on the best way to halt or slow cognitive decline in MS? Are there any 'mind' exercises or particular food that are proven to help?

**Patrick - OT:** There isn't much evidence to support the assumption that cognitive difficulties will always get worse over time. They seem to be the symptom that deteriorates the least in many people. A balanced diet and rest will help

generally. If you get anxious about an aspect of thinking, then that arousal will interfere with trying to remember or recall something. Using a relaxation technique to get calmer can improve recall.

**Hazel:** Thanks Patrick

---

**Julie:** Hi. I am having problems with mood swings and wondered if there were any supplements that I could take for these.

**Judy - MS nurse:** Hi, Julie. Mood swings are a problem. First - is it down to MS or could it be due to something else, such as a menstrual problem? Check that first.

**Julie:** It is down to my MS as when having pain I get bad mood swings

**Judy - MS nurse:** There are no supplements that have been proven to be effective but keeping a good basic state of health is important. If the swings are a nuisance, seek help through your GP. Get him/her to assess your moods. This is the important next step

**Julie:** I hear of people who are taking supplements generally for their MS and I get info from magazines. Are there supplements that I can take like vitamin B or D?

**Judy - MS nurse:** I see that that your mood swings when you are having pain, that sounds logical. Can the doctors improve your pain control?

**Julie:** I'm not very happy with my doctors at the moment as I'm not being given any medication that helps and in pain most of the time.

**Judy - MS nurse:** Have you ever been referred to a specialist pain clinic? You can be referred by your GP and have a right to be referred.

**Julie:** Yes, I have an appointment for next week.

**Jude:** Julie, I know what you mean. My specialist prescribed gabapentin, but its not that effective

**Julie:** I used to be on that then put me on new one called Pregabalin. I'm on the maximum dose.

**Julie:** I am also being very forgetful at present and don't know if this is normal or to do with my MS?

**Jude:** Would a pain clinic help me? I am not in pain all the time, but when I do get pain I find it unbearable

**Judy - MS nurse:** If you have tried gabapentin to no affect, a pain clinic would certainly be appropriate. What type is your pain?

**Rachel:** I've found my memory seems to be worse as the dose of pain relief increases

**Rosslyn:** [question sent in advance] I do not have memory problems, but concentration is harder now than it was in my 40s. This lack of ability to

concentrate is particularly obvious to me about 45 minutes after taking one of my three times daily tizanadine tablets [anti-spasmodic]. I find my attention wandering and my retention of facts feeble, unless I am watching a very good film! Do such drugs worsen an inevitable process?

**Judy - MS nurse:** Some drugs can have an effect, but that is very individual. It's good that you've recognised this. It may be helpful to talk to your doctor about alternative medications. As for hints for concentrating, take short spells of concentration and then have a break. Prioritise tasks. Use multi-sense input – see it, talk it, write it, listen to it – that way the brain can more easily retain information. Look at other factors that could be affecting concentration such as sleep – are you getting enough? – and nutrition – missing meals hampers concentration.

**Jock:** I would like to raise the matter of the efficacy of ginkgo biloba and research on it. I am 63, diagnosed with MS in 1992 - progressive sort (another word for insidious) and sit at about 3.5 on the EDSS. The gradual impairment of clear and quick thinking became quite a nuisance and a liability that threatened much of my functioning. The herb ginkgo erased that nuisance at 120 mg/day. But more - and surprisingly so - when increased in search of optimum dosage, gave me back my whole memory and my full cognitive abilities at 1200 mg/day. By periodic stoppage, I have confirmed ginkgo to be the singular correlate of this advantage in my own case at least. I would therefore like to recommend to others to try and see if they might find this leaf to alleviate their own 'brain fog',

**Patrick - OT:** Jock, some people do report benefits from herbal supplements. Unfortunately this isn't supported by research... so far. Provided you monitor for any other side effects or reactions, then it might be worth trying. Use a reputable supplier and don't exceed the manufacturer's dose. Check with your doctor as some herbs interact with prescribed medicines

**Jock:** With the threat of cessation of supply as the EU implements restrictions on such herbal remedies, I would hope that some company would search and discover the magic ingredient of this plant.

**Patrick - OT:** I understand the EU legislation is floundering, as it would be so hard to enforce

**Simon – MS Trust:** Jock, ginkgo has an effect on blood flow and so shouldn't be taken with blood thinning drugs (eg warfarin) or aspirin. People with bleeding disorders or who will be undergoing surgery should also avoid the herb.

**Julie:** Could someone explain the St John's wort to me and what it helps please?

**Jay:** St John's wort is a herbal remedy for mild depression. It improves your mood and seems to help

**Julie:** And the ginkgo is for the mind and thought process?

**Patrick - OT:** St John's wort is a different remedy, used as an anti depressant.

**Karen:** St John's wort is a herbal anti-depressant, but it can't be used with some drugs so always check

**Judy - MS nurse:** It is always important to consult with your doctor about herbal remedies. St John's wort interacts with many drugs that are used for MS, so beware

**Jay:** I always ask the chemist and/or GP about interactions, but they do not always know!

**Simon – MS Trust:** St John's wort should be used with care as it does seem to interact with a whole range of drugs, including several used to treat heart disease, cancer and prescription depression treatments. It can also counteract the effects of warfarin and oral contraceptives. Of specific interest to people with MS, St John's wort shouldn't be used when taking amitriptyline, carbamazepine, imipramine, phenytoin, nortriptyline, phenobarbital and primidone. Do ask your doctor to check that the remedy is not affecting any other medication that you are on. If they don't know off the top of their heads, they are able to look these things up for you.

**Judy - MS nurse:** Jay, yes, many professionals do not have that information about St John's wort to hand

**Simon – MS Trust:** It is also important to remember that St John's wort works on low mood rather than major depression.

**Julie:** I am very new to all these supplements and not one to like taking lots of tablets. Do you think that maybe I should be?

**Judy - MS nurse:** Yes supplements can be a problem. The important thing is to try just one at once then you can more easily judge its effect

---

**Kate:** Is there some information I can give to others to explain about the 'impairment and quick thinking' as Jock puts it. I'm finding it very frustrating that I can't explain it easily

**Judy - MS nurse:** Hints on concentration and slow thought processing include:

- directing concentration in short spans
- exclude distractions and only do one task at a time
- prioritise tasks
- reduce changes in your environment
- repeat, reinforce, review
- as with poor memory, multi-sense input can be helpful. For instance – see it (read), speak it (say it out loud), hear it (use tapes/dictaphone), write it down
- 

**Marilyn:** [question sent in advance] I stopped driving in 1999. Initially the problem was caused by a wrist fusion procedure but I still don't feel safe to drive. Lack of ability to operate the controls of a car is no longer the issue but the speed at which it and other vehicles move is. I make a nightmare passenger because I think we're going to hit something. Walking is slower so I feel safer but crossing busy roads is still tricky. Can you explain what is causing the problem for me?

**Judy - MS nurse:** This could be a problem with what is known as visuo-spatial functioning.

**Julie:** Re: visuo-spatial problems, I find an A-Z very difficult now, despite living in London all my life. Is this common?

**Judy - MS nurse:** Anyone had a right to be fog-bounded with the A-Z. Have you tried the A4 version. Or what an online map that gives you written directions too, such as the AA route finder ([www.theaa.com](http://www.theaa.com)) or Multimap ([www.multimap.com](http://www.multimap.com))?

**Julie:** No you misunderstand. I have used one all my life okay but now I cant relate it around me any longer. Also places like hospitals and schools are hard to find way round

**Judy - MS nurse:** Sorry to misunderstand, I see what you mean. It sounds like a visuo-spatial problems combined with slowness of processing information. It may be helpful to take a friend

**Julie:** I find a major problem is getting people to acknowledge there IS a problem. They tend to rubbish it and say I've got a bad memory too

**Kate:** I empathise with Julie. Getting people to understand is so difficult. Last year it was put down to anxiety, until a visual impairment officer saw me who picked up part of the problem

**Judy - MS nurse:** Where did you get your visual impairment officer from? I would like one to hand!

**Julie:** Sounds interesting Kate. Where did you find a visual impairment officer?

**Kate:** I am still having difficulty explaining what I experience, partly because it gets worse as I get tired. The ROVI (Rehabilitation Officer for Visual Impairment) got called in when I was 'handed over' to social services last year. She was good listener, and made helpful suggestions. She got me referred back to the optician at the eye unit who sorted out less strong glasses which have helped, but it is only part of the problem.

**Patrick - OT:** To go back to your problem, Julie - do you mean if you look at a map of a hospital, for instance, you then find it difficult to relate the information to the three dimensional world?

**Julie:** Yes, whether it's a hospital or the roads around I cannot convert what I see to what I have to do. It quite often panics me whereas I used to be able to direct anyone anywhere!

**Patrick - OT:** Try breaking down the route into chunks, eg to the next junction or corridor. Draw your route onto the A-Z and then only concentrate on the next road within your immediate area. Sometimes it is trying to manage the whole volume of information that triggers problems. The same is true if you are trying to think in a noisy environment. Find a quiet place or turn to a wall to reduce the 'interference'

**Julie:** That's very true about noise around. I also now have to have absolute silence - no radio - when doing figure work. I will try the turn to a wall idea but may get taken for a nutter!

**Patrick - OT:** The 'panic' will inhibit your ability so try learning a relaxation technique around controlling your anxiety. If you control your anxiety, you may find a lot of your abilities are retained but switched off or hidden by the effect of the worry

**Julie:** I accept that Patrick, but when you're on a street corner trying to decide which way to go it can be hard to go into relaxation mode

**Patrick - OT:** Many of the people I work with have found that they can't deal with the levels of noise, movement and bright colours in the High Street. It seems that the overall stimulation can overload thinking and they need to rest from it. The upside is that the effect is often passing and isn't a consistent problem. As regards being taken for a nutter - their problem not yours :-)

**Julie:** Thanks for that Patrick. I agree too on the High Street, and it also goes for pubs etc too. It's difficult to hear/concentrate or talk

**Patrick - OT:** Julie, you are right, but relaxation is like learning to ride a bike - hard at first and needs lots of practice, including going to a busy street corner and practicing the skill for a few minutes. Try holding a newspaper so you won't feel obvious

**Kate:** Thanks Julie and Patrick. So good to hear I'm not alone on finding it difficult at times being out.

**Patrick - OT:** The important bit is to keep going out as it is easy to become isolated. Try to hit the pubs at quieter times, though this is a contradiction if you like the 'crack!' The alternative is to choose pubs or bars that have rooms or booths where you can reduce stimulation. In nightclubs, use chill out rooms regularly so you don't get exhausted

---

**Alistair:** I was diagnosed with relapsing MS in 2002 but my first episode in 1995 comprised mainly fatigue/concentration. Is this unusual

**Judy - MS nurse:** First symptoms of MS usually include some sensory or functional disorder, but your test will have been conclusive for MS. It's unusual for it to present like yours but with MS - anything is possible.

**Alistair:** Thanks Judy. In fact I did have some transient sensory disturbance intermittently during the first episode. Now I have fatigue and sensory problems all the time! I do find that the fatigue and loss of concentration to be closely linked. Is this normally so or can they be independent?

**Judy - MS nurse:** Yes, fatigue is the pits! Do you have a friendly, local MS Nurse who could give you some hints on fatigue?

**Alistair:** Although my GP and neurologist have been supportive it was not until yesterday that I saw an MS nurse and it was like a weight lifted off me. She was great and has already referred me to other MS colleagues for depression, which hasn't helped the fatigue.

**Judy - MS nurse:** Loss of concentration is directly related to fatigue - can anyone think clearly late into the night or suffering loss of sleep? Focus on strategies for fatigue, and the concentration might also improve.

**Alistair:** I already have MS Society material on fatigue and will download the MS Trust material. I will also talk more with the MS Nurse.

**Alistair:** I will say cheerio for now as the concentration is beginning to go. Thanks Judy and Simon

**Ni:** Hi, thought it was time I joined!

**Simon – MS Trust:** Glad you could make it. Do you have a question?

**Ni:** Concentration and mood have become quite high on my 'MS ailments' list over the last six months or so (these and fatigue are new to me). What are the reasons behind mood swings and MS? Surely it's not the drugs or my relationship!?

**Judy - MS nurse:** Ni, hello. Your concentration and mood problems may have a root in depression. Has your GP investigated this for you? Look into this first. Reasons behind mood swings are varied. Drugs, menstrual cycle or relationships could all be the culprit as well as MS

**Ni:** I have found that taking time out, only short periods, during my working day aids in the length of my concentration span

**Judy - MS nurse:** Yes, it is terribly important to include short breaks - and don't forget time out for lunch and 'feet-up' at home time!

**Patrick - OT:** It is better to take regular short rests or breaks than work until you are exhausted. The real trick seems to be to stop or have a break just before you feel need one. A timer can help to remind you to do this

**GHR:** Hello, all. May I ask about a slightly different aspect - the relationship, if any, between cognitive problems and facial expressions? To explain, my husband is severely disabled and cannot speak. When I tell him something obviously sad or upsetting, he will still grin. Sometimes I don't know if he misunderstands or else can only grin (for another MS-related reason?)

**Judy - MS nurse:** Very occasionally people with MS can develop quirks of the brain that cause inappropriate responses, eg laughing or crying. The important thing to is continue to communicate. Has a speech and language therapist helped you at all?

**GHR:** Yes, we have had a lot of contact but have reached the end of the road. We use his rapid blinking as a means of communicating yes or no. He can't move hands at all... or anything else.

**Judy - MS nurse:** I do empathise with your situation, how very difficult for you both.

**GHR:** Thank you. With all the disabilities and losses we have suffered, I find this one of the hardest and least discussed.

**Judy - MS nurse:** Yes, this hits at the heart of all that you have been through, together. It is called pathological laughing/crying syndrome. It is rare but very distressing to your both.

**GHR:** This describes it well. On the positive side, his constant laughing, apparently in adverse situations, endears him to his other carers, so in a way it helps him.

**Judy - MS nurse:** Oh that is wonderful - behind every dark cloud, there is a spark of light!.

**Kate:** We are having a regional conference in Exeter on May 14 where a neuro-psychologist from Cornwall will discuss some of the problems with cognition and memory. Thought people might like to know this

**Simon – MS Trust:** Thanks Kate. Is there a website or contact number?

**Kate:** For conference contact details you can email the organisers on devonandcornwallmssociety@hotmail.com

**Diane:** [question sent in advance] I would like to know if word finding comes into the equation. I suffer from memory problems, and my concentration isn't too good. I follow all the necessary points, eg I leave the room should a phone call be for me to avoid distraction. Also, concerning memory, I leave little reminders, like notes, and have wipe board. I am able to do jigsaws and things like that. I have difficulty word finding though, and lose the threads of conversations, and need to be prompted, it does get me very depressed as well. I used to work for a communications company, and was in constant contact with my peers, and also customers, so as you can imagine, it gets me depressed. It has taken me two days to pull this email together. I would appreciate your help.

**Judy - MS nurse:** Try distracting or stopping your search for a word. Divert your attention, then have another try. This often gets to the word via a different route. At least with email you have the advantage of assembling your thoughts and only sending when you're ready. Don't give up.

**Kate:** is it possible to know from MRI scans if you will be particularly affected by cognition problems?

**Judy - MS nurse:** Interpretation of MRIs is the work of the neurologist and they may be able to make predictions, but not everything that is there on MRI correlates to symptoms.

---

**Sheila:** I have problems with conversation. I am unable to get the right words or phrase that I want to use

**Judy - MS nurse:** This is not an uncommon problem. Usually, it is easier to divert the track of a conversation and then return to the subject later. It is often the case, as brain gets tired through over-use. Try to stop, divert, try again. See if this works.

**Sheila:** I am in a professional job requiring me to communicate frequently in meetings etc. It has now become noticeable that I am having problems

**Judy - MS nurse:** I agree, that is an awkward problem. Do you have to run the dialogue or can you sit back and 'assemble' your thoughts?

**Sheila:** I often have to run the dialogue

**Judy - MS nurse:** The only way to get round this probably is to predict comments and answers that you may have to make. Also ask your GP to review any medications

**Sheila:** Thanks Judy. I also get frequent headaches - could this be related to MS

**Judy - MS nurse:** Yes. I have been constantly telling the neurologist that people with MS also get headaches and they always say it has nothing to do with MS. But people with MS know different. It can come about by walking in an awkward way that puts strain on the muscles, generating muscle strain.

**Glenn:** At the minute I am on Avonex, and having a hard time with it. How long before things settle down? I've been on it six months.

**Judy - MS nurse:** Do you have an MS therapy nurse to whom you can relate? You do not say 'how' things are affecting you?

**Glenn:** Yes I have an MS nurse. I saw her and the consultant last week. Problems are severe headaches, tiredness, and my muscles are all stiff. So far no benefits.

**Judy - MS nurse:** Glenn, it seems you are monitored well. Your symptoms are not uncommon. Usually if they think the injections are the problem - they stop for a short time to see if they clear. Most of all, talk this idea through with them - don't stop off your own bat!

**Sheila:** I also have problems with Avonex but manage symptoms with combination of paracetamol and ibuprofen. Sometimes it helps to anticipate when problems will start and take medication before that

**Glenn:** I take Ibuprofen before injection and two day afterwards. I asked if I could stop the injections but was told to keep up with them for another ten weeks.

**Judy - MS nurse:** Yes, that was going to my next suggestion.

**Pippin:** I worry so much about my cognitive problems

**Judy - MS nurse:** I'm sorry about your cognitive problems. What seem to be the chief culprit?

**Pippin:** Due to my eyes I can not drive

**Judy - MS nurse:** Your vision can let you down at times - meaning no transport. Do you have a local volunteer car scheme?

**Pippin:** It also affects my spelling and 3Rs. I was a teacher

**Judy - MS nurse:** Writing via a computer with spellchecker can overcome the problem. I'm sure you have thought of this though. It must be very distressing for you.

**Simon - MS Trust:** Lyn, what sort of cognitive problems do you come across in your work as a speech and language therapist?

**Lyn - SLT:** As a speech and language therapist (SLT) I look at language - word finding difficulties, forgetting names, also the processing what people say to the individual, ie difficulties in understanding. There are so many strategies you can use to make life easier

**Simon - MS Trust:** Do you have any advice for Sheila and the problem of finding the right words whilst running meetings?

**Lyn - SLT:** The basic advice is to try a different word or talk round it

**Lyn - SLT:** Have you seen an SLT and had an assessment?

**Sheila:** No Lyn, I have not seen an SLT. How could that help?

**Lyn - SLT:** You can access speech and language therapy via your GP or many places have an open access system when you can phone up directly to local SLT department

**Simon - MS Trust:** We had an article on speech and language therapy in Open Door, our newsletter in May 2004. You can find this online at [www.mstrust.org.uk](http://www.mstrust.org.uk) or email your postal address to [info@mstrust.org.uk](mailto:info@mstrust.org.uk) and we can send a copy

---

**Barry:** I get head pain in bed is nurofen ok long-term?

**Judy - MS nurse:** Is your nurofen 'self' medication? Long-term use of these drugs can cause problems. Does your GP know? Is it working?

**Barry:** My GP prescribes 'meltlets'. Usually one is enough

**Judy - MS nurse:** I can't find 'meltlets' in my pharmaceutical directory. Any ideas what it contains?

**Barry:** They are over-the-counter self dissolving ibuprofen

**Judy - MS nurse:** OK, yes. These can cause stomach and gut problems if taken long-term, as with aspirin. Be careful. But, if it works, it rather indicates that inflammation - treatable with nurofen - is the culprit.

**Barry:** Why do I get pain only in bed most nights, but not all the time?

**Judy - MS nurse:** That's is the \$64,000 question. I may be likely that pain originates in the neck muscles, causing a headache. Thus, when you lie down, the pain comes. Does that seem realistic?

**Barry:** It's not the same as a headache, but what you say makes sense

**Judy - MS nurse:** Often patients tell me that their 'headaches' are not the same as ordinary headaches! Severe, nonetheless. But if the meltlets work - at least you have some relief.

---

**Sheilah:** I'm wondering what therapy there is now for visuo-spatial awareness problems

**Judy - MS nurse:** I posted some coping strategies for visuo-spatial problems earlier. There is no medication available really

**Sheilah:** That's OK, I don't want any medications

**Judy - MS nurse:** That's fine. Medications can complicate things. But the coping strategies may be useful and don't cost anything!

---

**Judy - MS nurse:** For general info, many things can affect brain function – including:

- sleeplessness
  - nutrition
  - constipation
  - multiple medication
  - lack of fluids
  - any infection brewing!
- 

**Sharon:** has anyone had memory problems to the extent that they do not know where their partner lives, when he in fact lives in the same house!

**Judy - MS nurse:** That appears to be very short-term memory loss, which is not usual. At the time, was your MS troublesome?

**Sharon:** I was having double vision and I was told it was causing problems with my frontal lobes. I am very worried that it will return, or that I will get Alzheimer's

**Judy - MS nurse:** I don't think there are any predictors of Alzheimer's. Inflammation in the brain (active disease) may give you the problems - but these can come and go

**Sandy - Psychiatrist:** There is no relationship between Alzheimer's and MS. They are two completely different conditions

**Sharon:** I have had severe constipation for at least a year, which has been investigated, and I have been given enemas to take when desperate. I also have frequent bouts of cystitis.

**Judy - MS nurse:** These could certainly contribute to MS symptoms. Is your constipation being checked occasionally? Also cystitis is common and the cause should be treated

**GHR:** As regards memory problems, my husband with MS thought we had been married 11 years - when in fact it was 22. He also forgot that we spent one year living in a different village before moving to our current house 12 years ago. These are big things to forget.

**Judy - MS nurse:** It would seem that one whole area of his memory is lost to recall. Are you getting enough help in your task of looking after him?

**GHR:** Yes, I agree. It is so sad that the past is lost in this way as well as everything else

**Jude:** I have found if you have constipation you become stressed and this leads to memory problems. I use Fybogel and drink lots. Stress is something to be avoided if possible

**Judy - MS nurse:** Yes, constipation causes reabsorption of toxins into the body, which is not MS friendly - either for muscles or memory! How much Fybogel are you taking? It can lead to problems if taken in large amounts. There are other products but if it works for you - OK

**Jude:** I only use it occasionally when I feel I need it, have taken advice on its use from my doctor.

**Judy - MS nurse:** That's great. Mention it to your MS nurse if and when you see her.

**Jude:** I find I have problems with concentration. Is there anything I can do to help? I am about to start a course and although looking forward to it am worried about my concentration span.

**Judy - MS nurse:** Aids for concentration were mentioned earlier in the session. The trick is to study in short bursts and then have a break - but not too many biscuits or the waistline expands!

**Patricia:** [question sent in advance] I have had relapsing/remitting MS for about 12 years. I now find my short-term memory is very bad and is now affecting my work. Could it be the MS, or the menopause, or the effects of venlafaxine? I take 75mg a day. Does any one else have similar problems?

**Alice:** I forget what I'm saying halfway thru' sentence. Is it my age (58) or my progressive MS?

**Judy - MS nurse:** Many people without MS have the same problem but don't own up to it. It's maddening. It could be a little bit of both. It is worth remembering that everyone's memory decreases over time - some more than others. Some women report that the menopause has an effect too. Also bear in mind that any drugs that act on the central nervous system can have the effect of reducing memory.

**Jude:** Sometimes I forget what I saying halfway thru a sentence, especially if I stop for a moment

**Alice:** Thanks for the comforting reply

**Judy - MS nurse:** This is not an uncommon problem. The best way is to cover-up by diverting the conversation yourself and then coming back to it. Look at the comments throughout the session and you will see that you are not alone

**Simon - MS Trust:** Thanks to Judy who has now left the chatroom to brave the M25

**Simon - MS Trust:** Hello Sandy, welcome to the room

**Sandy - Psychiatrist:** Hi Simon, it is good to be here.

**Simon - MS Trust:** Sandy Burnfield is a psychiatrist with personal experience of MS. Does anyone have any questions?

**Jude:** Does Sandy think talking to a counsellor would help me come to terms with my illness and cope with my mood swings, which are putting my marriage under a great deal of strain

**Sandy - Psychiatrist:** MS is very stressful emotionally and a great strain on relationships. It is often helpful to share feelings and learn ways to help each other. Many health and social professionals have counselling skills, as well as formal counsellors and therapists. Sometimes partners and kids also feel sad angry or scared. So, Jude, yes it is a good idea to talk about feelings and frustrations, and get new ideas on coping better. Mood swings often occur in MS and may be part of depression - very common in MS - and not necessarily due to cognitive issues

**George:** It is very true that other people's relations to problems throw up new and different problems, particularly things like my bad memory which people dismiss as almost laziness on my behalf

**Sandy - Psychiatrist:** MS does not just affect one person - family and friends and work mates have it too in many ways! People often have little idea about how MS affects us invisibly - like fatigue and memory problems etc...

**George:** Yes, I do get the same thing with my fatigue

**Sandy - Psychiatrist:** We have to educate them ourselves which is just an added problem sometimes

---

**Jude:** Sandy, how do you know if you are depressed?

**Sandy - Psychiatrist:** If you are depressed you sometimes don't realise. But if you feel sad and hopeless most of the time, have lost interest in things and have appetite or sleep changes you may be clinically depressed and respond to therapy. Sex life too can be affected putting extra strain on partners. Depression is VERY common in MS and understandable. It is a good idea to talk about these things with a nurse or GP

**Jude:** I do have bouts of sleeplessness and often a poor self image and a feeling that people are looking at me and wondering why I am using a walking stick or a wheelchair

**Sandy - Psychiatrist:** It is hard using a stick and wheelchair. Most people feel like that at some stage

**George:** I know that I have had big problems with self image too

**Sandy - Psychiatrist:** Losing our self image is one of the most difficult things we have to do with MS - this loss often leads to depression and even feelings of self hate or suicide

**Naz:** I just feel low and would love to chat

**Sandy - Psychiatrist:** Sorry that you feel low. This disease is enough to drive us all to depression at times

**Naz:** I have a three year old son and live alone. My MS is getting worse

**Sandy - Psychiatrist:** That must be very tiring and scary, Naz

**Naz:** My GP prescribed Prozac but I have not taken them. I long for a cuddle

**Sandy - Psychiatrist:** Yes, medication does not necessarily get rid of the stress. We all need love, understanding and affection most of all, Naz. It is brave of you to say these things

**Naz:** It does not help being indoors alone everyday but who would want me now?

**Sandy - Psychiatrist:** It is important for you to have some breaks and rest, but it must be difficult for you and you seem to have lost confidence in yourself. Have you got anyone close you can talk to?

**Naz:** Yes I have family and yes I feel many losses

**Sandy - Psychiatrist:** There are no easy answers. Loss is hard, and we need to share our grief and pain

**George:** Many losses seems to describe MS well (though I think the name means many scars)

**Sandy - Psychiatrist:** You are right George - in both respects. MS can be a series of losses and it is difficult to see any gains

**Naz:** I am only 33 years old had a very active life, and now cannot even take my son to the park

**Sandy - Psychiatrist:** I am glad you can share this with us - you are brave, and also helping many others who will read this transcript and feel less alone

**Naz:** I have been offered beta interferon but feel angry was not offered seven years ago when I was diagnosed

**Sandy - Psychiatrist:** There are lots of views about beta interferons. It is frustrating when you feel it could have been offered it earlier, no wonder you are angry. Can you talk to your MS nurse, Naz?

**Naz:** Little to say as I have spoken to the nurse. She just feels I should take it but again damage has been done

**Sandy - Psychiatrist:** Hard to take that, but may be worth a go now, Naz

**Naz:** I know but have also questioned if being on interferon will make me so down as I will be having to have injections rest of my life

**Sandy - Psychiatrist:** These are not easy decisions, Naz. Take your time to decide. Look at the evidence with the MS nurse and sift out the pros and cons.

**Simon - MS Trust:** There is a website for people considering going onto these drugs at [www.msdecisions.org.uk](http://www.msdecisions.org.uk). The MS Trust booklet that gives an outline of the drugs is available on our website [www.mstrust.org.uk](http://www.mstrust.org.uk)

**Dawn - Psychologist:** Naz, the studies of people with MS show no increase in depression for people giving themselves the injections over several years

**Simon - MS Trust:** Dawn Langdon has now joined the room. Dawn is a neuro-psychologist

**Linda:** Who do I see for a cognitive assessment - psychiatrist or psychologist?

**Sandy - Psychiatrist:** Your GP could refer you to a clinical psychologist - they deal with those assessments

**Dawn - Psychologist:** I am a clinical neuro-psychologist. A cognitive assessment is usually done by a psychologist.

**Diane:** [question sent in advance] I am going to see a neuro-psychologist this month, and want to know what the test involves.

**Linda:** What does an assessment involve and is there follow up treatment that can improve cognitive impairment?

**Dawn - Psychologist:** A cognitive assessment consists of tests, like quizzes and puzzles, which measure your memory, concentration etc. Your performance is evaluated by comparing your scores with people of your own age. Treatment for cognitive problems often addresses a range of targets.

**Simon - MS Trust:** The experts online at the moment are Sandy, a psychiatrist, and Dawn, a neuro-psychologist.

**Lyn - SLT:** There's a speech and language therapist out here too

**Dawn - Psychologist:** Yes of course, speech and language expertise is very important. Do you do a lot of work with people with MS, Lyn?

**Lyn - SLT:** Yes. I am in the fortunate position of seeing only MS patients. I work for an MS therapy centre. Many folk have found it helpful to chat about speech, swallowing or word finding. It can help to work with partners to help them change the way they communicate

**George:** How do you mean change the way they communicate? What does this involve?

**Lyn - SLT:** Sometimes it helps to slow down, face the person - all sorts of small tips. Ask for an SLT referral or give your local hospital department a ring direct

**Sandy - Psychiatrist:** What sort of cognitive problems do you experience, Jonathan?

**Jonathon:** I'll try and explain. I have five businesses; some involve family as partners and other partners. I see that I have ultimate responsibility within my business.

**Sandy - Psychiatrist:** Could you explain the issues a bit more Jonathan

**Dawn - Psychologist:** You could ask your GP for a referral to a neuro-psychologist, or email the MST on [info@mstrust.org.uk](mailto:info@mstrust.org.uk)

---

**Kate:** Last July I saw a neurologist who did would not consider me for disease modifying therapy as she could not distinguish which symptoms were MS and which were stress. Long term family problem now over. I wanted to now more about how stress affects physiology and how or if the body adapts when no longer in stressful situations. Don't know if I have the right term, but something to do with cortisol (?)

**Dawn - Psychologist:** You could ask for a second opinion. Ask your GP to send you to a neurologist who specialises in MS

**Kate:** I was seeing the neurologist at the rehab unit

**Dawn - Psychologist:** You are entitled to a copy of the neurologist's letters (ie opinions) about you and you can ask for a second expert opinion.

**Kate:** I saw all my GP notes in January, including the letters from this neurologist and the one I saw when first diagnosed. The GP said I could have a second opinion but would be someone out of the area. As I am almost housebound this would be difficult, and due to tiredness and 'slow thinking', I'm not sure I would gain much

**Dawn - Psychologist:** If you were refused drugs on the basis that the neurologist could not tell stress symptoms from MS symptoms, or you believe that you were, get to someone who can tell the difference

**Kate:** How do I find someone how can?

**Dawn - Psychologist:** There are ways that the fatigue symptoms can be tackled

**Kate:** At present I feel no support from GP, MS nurse or neurologist and with the slow thinking don't know how to make myself understood

**Lyn - SLT:** Kate, try having someone with you to help process and retain what is said. You could take a dictaphone with you and record for playback if the other person agrees

**Kate:** Someone from patients' liaison (PALS) came to my last appointment

**Lyn - SLT:** It might help to take friend or family member who can talk it over with you longer term

**Kate:** Part of the problem is I now have no family and because last year mental health issue were being raised instead of MS and slow thinking etc it is very hard for friends to get involved - they are treated as if family carers

**Dawn - Psychologist:** I am sorry that you feel there is no one supporting you. I think it would be worth getting a second, expert neurological opinion

---

**Simon - MS Trust:** Patrick Carroll, an occupational therapist has rejoined the session. Currently we have Dawn, a psychologist, Sandy, a psychiatrist, and Patrick, an OT, online.

---

**Jerry:** I've been following the MS diet forum recently and wondered whether people really do benefit from the Best Bet diet? My husband has MS and is finding it very difficult to follow the diet

**Simon - MS Trust:** No trials of Best Bet diet as yet, but I believe they are trying to set something up

**Sandy - Psychiatrist:** There is no particular diet for MS - just the healthy one for everyone

**Jerry:** The problem is he hasn't seen any real improvement. How long does it take to see any results?

**Jude:** what is the Best Bet diet?

**Jerry:** A diet with no dairy, no gluten, no legumes etc

**Sheilah:** I am on the diet.

**Jerry:** Has it helped you?

**Sheilah:** Yes, in every way. Especially memory right away.

**Anna:** I hope you are still getting sufficient calcium if you are on a restricted diet. Especially important in women!

**Simon - MS Trust:** Jerry, the individual is probably the best person to gauge the value of a diet. If it seems to be doing good and is providing sufficient nutrition, keep doing it. If it doesn't seem to be working, maybe it's time to chalk it up to experience and try something different.

**Jerry:** My husband is also on low dose naltrexone (LDN) but not seeing any improvement either

**Simon - MS Trust:** Same applies to LDN

**Sandy - Psychiatrist:** No evidence for LDN either

**Harry:** What is LDN?

**Simon - MS Trust:** Naltrexone is normally used for drug withdrawal management at high dose. LDN is a therapy based on a low dose of the drug. There is some anecdotal support for the therapy but as yet little research has been done.

**Jerry:** I found loads of anecdotal evidence but so far the real thing hasn't had much effect. Apparently lots of people find it helps with energy levels and other things.

**Patrick - OT:** The proponents of LDN say that it will treat a range of conditions including MS. The problem is that LDN proponents seem to say it'll help with everything

**Simon - MS Trust:** Jerry, I'm not sure how quickly LDN is supposed to kick in. Cost is also an issue, as value for money from treatment is important. Does the cost justify continuing?

**Jerry:** I want him to follow the diet, but he wants to jack it all in and go back to eating pizza

**Sheilah:** I wonder if he takes lecithin, or ginkgo

**Jerry:** He takes some evening primrose oil, fish oil, B12, but not ginkgo

---

**Linda:** I have been experiencing severe vertigo/loss of awareness & balance problems, which greatly affect my cognitive function. I had steroids recently but am no better. Any ideas?

**Dawn - Psychologist:** Physiotherapists can treat vertigo and balance problems in most cases. Ask for referral to a neuro-physio. I am not sure why the balance problems should affect cognition, unless they both compete for scarce resources?

**Alistair:** I've been offered Modafinil or amantadine for fatigue. 1) Do they work? 2) Are there side effects? 3) Is it short lived?

**Sandy - Psychiatrist:** Yes, those drugs can sometimes help

**Simon - MS Trust:** The MS Trust has a factsheet on fatigue that touches briefly on the medications. You can download this from [www.mstrust.org.uk](http://www.mstrust.org.uk)

**Sandy - Psychiatrist:** Check out the issues with an MS nurse or neurologist. These drugs are safer than pemoline

**Dawn - Psychologist:** Both of the drugs you mention have been used for fatigue, but how useful they will be for you and what side effects may occur can only be assessed in your own personal situation

**Alistair:** Thanks for this. Having seen an MS nurse for the first time yesterday I will certainly take it up.

**Linda:** Is worsening of cognitive impairment an indicator of disease progression?

**Dawn - Psychologist:** Cognitive abilities are related to disease activity, but cognitive difficulties can come and go, that means occur and recover, like other symptoms

**Lyn - SLT:** It might also be related to other things like infection or dehydration

**Alistair:** Can the extent of cognitive impairment be objectively tested by psychologists or is it just assessed on what the MS patient says?

**Dawn - Psychologist:** Yes, objective assessment is possible on a range of tests, like quizzes and puzzles. Your scores are evaluated by comparing them to people of your own age

**Alistair:** Are these tests specifically for MS or are they used generally for cognition problems?

**Dawn - Psychologist:** There are generic tests of cognitive function but there are also batteries specifically developed for and used in MS

---

**Linda:** Kate, I have also been told to see a psychiatrist, when I need to see a psychologist. So you are not alone, but what do we do about it? Anyone else any ideas?

**Dawn - Psychologist:** It may be that the psychiatrist can help. What are your difficulties?

**Kate:** I'm trying to understand the physiology. I feel I have had normal grief reactions to difficult situations. I saw a psychologist a couple of years before getting optic neuritis, which was four years before getting the MS diagnosis. During that four year period, what I now know to be MS symptoms were put down to anxiety, panic attacks or depression. Even the numbness and tingling in my limbs was said to be secondary to anxiety. Then the psychologist said I had something physically wrong with me but was not investigated properly

**Dawn - Psychologist:** Kate, I understand your frustration, but sadly for some people the first symptoms of MS are not clear and diagnosis can take years

**Kate:** Last year I mentioned the guidelines about proper assessment for people with MS, so not everything is put down to MS, but it seems once you have MS diagnosed it gets difficult to distinguish other things

**Sandy - Psychiatrist:** Once you have got one disease you may not be allowed another!

**Kate:** Yes Sandy, yes, but life is not like that

**Sandy - Psychiatrist:** You are right, Kate, life is not like that. But sometimes professionals take short cuts and don't spend long enough with patients. That has to change

**Kate:** Thank you Sandy - that is what I'm learning. And it is really useful having chatroom like this to hear problems others with MS are dealing with, as it can get quite isolating. Earlier today it was useful hearing of someone having similar experiences about visual and slow thinking, which to me helps me understand that much is just another part of MS that I need to adapt to, like not being able to drive, changes in work etc

**Dawn - Psychologist:** I am sorry to hear that things are such a struggle for you. Is there any mileage in asking to be allocated a social worker?

**Kate:** I was referred to social services last year when I had a relapse that left me unable to walk for the first time. Now I have improved so that I'm no longer eligible for their services. The care manager was the OT I had seen before - a good guy - and it seems I have to sort things out myself. I was very angry when I read my GP notes and that is now subsiding.

**Sandy - Psychiatrist:** In the modern NHS and social services, financial targets seem to be more important than meeting needs - a political issue!

**Dawn - Psychologist:** What did your social worker do or say last year? Can you ask your GP to appeal the decision that social services closed your case - and get the case manager back

**Kate:** Not appropriate, he explained the situation to me. It also relates to funding etc.

---

**Linda:** I have been told by a neurologist to go away and accept the MS rather than them explore my physical symptoms. I feel I am being brushed off.

**Dawn - Psychologist:** Can you get to someone who can discuss these feelings and symptoms knowledgeably with you?

**Sandy - Psychiatrist:** It is often easier for doctors to deal with physical problems than emotional or invisible ones. We have to educate them. The MS nurses are often good listeners

**Dawn - Psychologist:** An MS nurse may be a first step - details from [info@mstrust.org.uk](mailto:info@mstrust.org.uk). Information may also be helpful, the MS Trust website has info, also the MSIF website ([www.msif.org](http://www.msif.org))

**Em:** Hi. I've been dizzy, wobbly and had double vision for months now. My mood is not happy as I can't work etc. What now?

**Sandy - Psychiatrist:** Must be very scary for you Em. It's not surprising you feel low

**Em:** Good way of putting it. Mood swings abound and I can't always have a brave face.

**Dawn - Psychologist:** Do you have any family or friends that you can talk to?

**Em:** I have my partner, who's just as fed up, but strong. It's tough. My family just worry, which is negative. I'm no longer pretending to be happy and coping, so I feel like I've limited my life... Not always like that though.

**Sandy - Psychiatrist:** It is not easy to act happy when you feel sad. It can lead to even more stress. Mood swings are very common in MS, as is depression at times. These things are best shared if possible, maybe with a good friend, or sometimes an MS nurse or counsellor

**Kate:** I sometimes think it might help if there was mention of bereavement when depression is suggested, as I found I have to grieve the loss of the person I was before MS. Otherwise I have no chance of finding who I am when MS always has to come along

**Sandy - Psychiatrist:** That is very well put Kate. MS seems to mean one grief process after another sometimes

**Kate:** On my medical notes there was mention of depression, but not bereavement, and there has been more than one death that deeply affected me. Is there sometimes a confusion in attributing some normal part of the bereavement process with depression? Both can be very painful.

**Dawn - Psychologist:** I am very sorry to hear about all of these burdens you carry and I sense you are hurting very much and feel that no-one is listening

**Sandy - Psychiatrist:** One bereavement after another can deplete mental energy and eventually lead to clinical depression

**Kate:** Yes, but I have not been clinically depressed. At times there just has not been enough of me to go around MS feels like that frequently, and I am learning I have to adapt my expectations to my energies and even then do less

**Sandy - Psychiatrist:** But bereavement grief is very understandable and should not be labelled a psychiatric problem unless there are complications

**Anna:** Fatigue can exacerbate feelings of depression or low mood

**Sandy - Psychiatrist:** That must be very frustrating, Kate, but you seem to have worked out a good strategy to deal with making the best use of your energy

**Patrick - OT:** Lots of people with limited energy tend to give up pleasurable activities and hold onto the 'chores'

Yes Sandy, it is coming together slowly. It's not a smooth process and I find being given information, especially the 'bad' side of MS helps me more than feeling dismissed.

**Sandy - Psychiatrist:** Yes, it is better to know what we are up against, Kate, and we deal as best we can - sometimes its is easier than others

**Kate:** I have yet to find a strategy for dealing with frustration. What the MS equivalent to a good long walk?

**Patrick - OT:** Have you thought about learning a relaxation technique?

**Sandy - Psychiatrist:** Exercise of any sort will help you feel better as long as it is appropriate to your own abilities eg riding, swimming if possible

**Anna:** Yoga has been shown to be relaxing to people with MS and other long term conditions

**Kate:** Yes I know about relaxation and regularly have individual sessions with a yoga therapist. Swimming is not on at present

**Simon - MS Trust:** The MS Trust has a CD-ROM called Be Inspired Stay Active, which is full of ideas for activities from team games to yoga - contact us at [info@mstrust.org.uk](mailto:info@mstrust.org.uk) and we can send you one. We also have a book called Exercises For People With MS

**Kate:** Does walking 'change the physiology'. That does not seem possible when experiencing MS tiredness

**Patrick - OT:** Kate it may have been the getting out that helped

**Kate:** I have recently have found crosswords help, as I guess that distracts me

**Anna:** Have you tried relaxation tapes? I find it hard to get my mind to stop working but this worked for me!

**Sandy - Psychiatrist:** So Kate, it is about using your mind - awareness and new experiences as well as exercise?

**Kate:** Using my mind is not the same as doing something physical. There is a good feeling after physical activities on good days

**Patrick - OT:** Try doing something physical for a very short period to start and then build up. Choose the best time of day.

**Sandy - Psychiatrist:** Yes, we all need that sort of exercise but you are finding you are too much in your head, Kate, and can't find an appropriate helpful exercise? Have you tried swimming or yoga?

**Kate:** Yes, I have had an active mind, and find it difficult accepting the impairment MS brings.

**Anna:** Have you tried massage or reflexology? They can help you on a bad physical day?

**Kate:** Yes, Anna, I have had reflexology for some time and find it helpful.

**Anna:** Massage needs to be from someone who knows about MS! Avoid over manipulation of the spine

**Kate:** It has been helpful today to know I'm not alone in experiencing cognitive problems, and I think it will help me communicate some of the difficulties I am having to the neurologists

**Sandy - Psychiatrist:** Thanks for sharing so much that will help others, Kate

**Anna:** Kate: Do you meet with any other people affected by MS?

**Kate:** Yes I do, but sometimes I find it makes me feel I have been labelled. And at times I find it scary to see what I may (or may not) have to deal with.

**Anna:** I can understand that, most people hate to be labelled!

**Patrick - OT:** I think it the whole uncertainty bit about MS that wears people down. We all carry a sort of future plan in our heads and MS takes the idea that this is certain away

**Kate:** One of my phrases before MS was to be "secure within insecurity" - learning that with MS deepens the yoga bit about living in the now and awareness

---

**Pat:** Hi, I'm interested in help to remember people's names

**Patrick - OT:** There is a technique of attaching a silly picture or thought to a person's name.

**Pat:** can you explain more

**Patrick - OT:** Well if a person's name started with a C, you imagine them up to their neck in custard, for instance

**Dawn - Psychologist:** It might be easier to try remembering a picture of them in a situation allied to the name e.g. Dave Hunter galloping after a fox on a giant D

**Patrick - OT:** Good example Dawn

**Dawn - Psychologist:** Or it might be more complicated and need a bit more planning and possibly written strategies to study

**Anna:** Patrick do you mean that it's easier to remember pictures than words?

**Dawn - Psychologist:** Some people find pictures easier to remember because they can be generated to be silly or funny, which makes them more memorable

**Pat:** OK, I will try that. I also seem to have a word finding difficulty any ideas?

**Patrick - OT:** Try running through the alphabet for the first letter or describe the action of the word

**Simon - MS Trust:** Hugh Rickards, a neuro-psychiatrist, has also joined the session. We now have a psychologist, a psychiatrist, a neuro-psychiatrist and an occupational therapist online

**Carol:** Is it true that people with primary progressive MS have little cognitive symptoms because the lesions are in the spine as opposed to the brain?

**Patrick - OT:** There doesn't seem to be a correlation between lesions and effects or symptoms

**Hugh - neuro-psychiatrist:** People with primary progressive MS can have lesions in the brain and they can also have cognitive symptoms

**Dawn - Psychologist:** There is conflicting evidence about how the degree of cognitive impairment in primary progressive MS compared to other subtypes of the disease. Because primary progressive MS is a rarer form there are not many studies. An Italian study, with small numbers, suggested that people with primary progressive MS had less cognitive impairment than those with secondary progressive MS. But a second, bigger, UK study showed people with primary progressive MS were experiencing significant levels of cognitive impairment. It does seem to be true that PPMS people on average have fewer brain lesions on MRI scans. But lesions on MRI are not the whole story as far as cognitive skills go - there are microscopic changes that affect cognition

**Sam:** Hugh, excuse my ignorance, but how does a neuro-psychiatrist fit into treatment of MS? Sorry, that sounds rude but not meant to.

**Hugh - neuro-psychiatrist:** We sit between neurology and psychiatry. We often see people with psychiatric symptoms who also have a neurological diagnosis or groups of symptoms that come between (like fatigue or sleep problems)

**Anna:** Are the people you see with MS with psychiatric problems more like to have primary progressive MS or have lived with MS for a long time?

**Hugh - neuro-psychiatrist:** Not really. People have the full range of symptoms and severities. Different psychiatric problems present at different times

**Anna:** Please slap my wrist if I sound rude but is everyone aware of the meaning of the term cognition?

**Hugh - neuro-psychiatrist:** Anna not at all rude.

**Dawn - Psychologist:** Cognition is a word that covers memory, concentration, finding your way, naming - all mental skills

**Kate:** I think one of the things I wanted to ask is how physiology affects thinking and especially in MS, but I don't think physiology is the right word to get over what I'm wanting to know.

**Dawn - Psychologist:** Lots of things can affect thinking in MS. One thing is how the disease is affecting the brain directly -which can come and go, or later on,

progress. Another thing is mood. We know that depression in MS limits the capacity of people to think of many things at once. Another thing is fatigue - people with MS will sometimes get worse over time when they repeat a task, such as remembering digits. There are also secondary things, such as infections, or even drugs given to treat symptoms (eg urinary dysfunction)

**Em:** Obviously mood heightens when relapses are in remission. Obvious connection, eh?

**Hugh - neuro-psychiatrist:** Not always Em. Sometimes mood can heighten in a relapse period

**Kate:** I know that alcohol affects thinking, but the other end is endorphins. Can the experts say what things we can do in our everyday lives that can help keep the cognition as good as it can be?

**Patrick - OT:** I'm reluctant to tell anyone to give things up. Moderation seems to be the answer

**Hugh - neuro-psychiatrist:** Thinking, feeling and perceiving are all things that the brain does. When MS affects the brain, then these things can be affected too. It depends a bit on what is affecting the cognition in first place. So looking at the cause of the cognition problem is probably the best start

**Kate:** What we think, eg happy rather sad, and emotions are affecting the brain, affecting its chemistry. I think it is why I was trying to make the point earlier that bereavement needs recognising and working through

**Sandy - Psychiatrist:** We can do lots of things Kate but need to know the cost to our health so we can make choices eg late night might mean a bad next day - but may be worth it

**Dawn - Psychologist:** There is support available specifically for bereavement issues. If you can't get this through your GP, you might want to contact the bereavement charity CRUSE [www.crusebereavementcare.org.uk](http://www.crusebereavementcare.org.uk)

**Kate:** CRUSE is great

**Anna:** Perhaps keeping a daily diary would help to identify what factors affect cognition?

**Hugh - neuro-psychiatrist:** It can definitely help, Anna

**Kate:** Hugh, how do you get the cause of the cognition problem properly diagnosed?

**Hugh - neuro-psychiatrist:** Good question Kate. You need to consult with someone who knows how to diagnose things! You need to be aware of many factors. Tiredness. Sleep problems. Depression. Anxiety. Cognitive 'overload'. Other physical things (infections etc). MS plaques. Actually, an interdisciplinary team is usually best at making the right diagnosis

**Kate:** What should I do the interdisciplinary team all say anxiety, and I don't agree with them?

**Hugh - neuro-psychiatrist:** A tricky one without knowing all the details. What do you think it is Kate?

**Dawn - Psychologist:** Anxiety treatment is usually effective and simple. Would you be very angry to think about it? It might help reduce the MS symptoms

**Kate:** I don't mind having mental health problems if that is what I have, but I have asked the GP etc to give full details to my attorney as it is no good telling me that they are referring me to a psychologist - long wait - when I think I have cognition problems relating to MS. Today has helped me understand more about MS cognition problems, but now it is getting the help.

**Dawn - Psychologist:** I know I have said this before, Kate, but the more I hear, the more me feeling is that you need an expert second opinion to devise a management plan for you

---

**Kate:** Thanks for listening to me today as I do need to persist with this

**Anna:** Kate, I hope you get all the support you need. All the best to you and everyone on here affected by MS. Bye for now

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

---

**Patti:** I have always been of the opinion that you have to keep on doing the things you have always done, even if they become difficult. Sooner or later another part of the brain will take over. That has certainly been my experience

**Patrick - OT:** You may have to try doing things different ways but focusing on the achievement is a good motivator

**Patti:** Motivation aside, I feel some people give up far too easily

**Patrick - OT:** Well, it is different strokes for different folks. Everyone is different as are their problems, despite a common diagnosis

**Patti:** Of course. I actually had more problems before I was diagnosed - (four years ago). I am a musician and a teacher. I used to find myself forgetting words - particularly technical terms for things that I have used all my life. I also found that I seemed to have to relearn how to play the piano every now and then

**Patrick - OT:** What helped after diagnosis?

**Patti:** When diagnosed, I changed my diet - started exercising. It made a big difference. I have an extremely heavy workload - teach full time, compose (published) regularly, have kids doing exams, concerts, competitions etc

**Patrick - OT:** Have you discussed your workload with your employer?

**Patti:** Why? I thrive on it. It's what I love doing and I feel that is a very important factor in staying on top of the MS

**Patrick - OT:** That's great. If it's not a problem, keep doing it

**Jude:** I agree with Patti. Exercise helps. I feel better after exercise.

**Patti:** Everyone gets depressed - and I think we have a right to be depressed sometimes. The problems happen when people are trying to push away the depression all the time. It makes your arms ache that does

**Patrick - OT:** I agree there is something important about accepting how we feel.

**Patti:** Some of the problems I have experienced, albeit intermittently, are much like those of someone with dyslexia – sequencing, following directions, particularly visual things (arrows and the like). But perseverance usually sorts it out in the end.

**Kate:** I have had dyslexic type problems long before MS was mentioned, and it was this that the rehabilitation officer for visual impairment (ROVI) (mentioned earlier) picked up on

**Patrick - OT:** Try breaking things up into smaller chunks to process

**Patti:** It's not usually a problem. Once or twice finding hymn numbers I found myself going the wrong way. Also, I have realised that I have had Irlen syndrome for all of my life but not badly enough to cause me real problems. Worse since I had optic neuritis. I think optical problems cause a lot of other problems that people put down to cognitive impairment, as in dyslexia

---

**Kate:** Hugh, can you suggest what kind of expert I should ask to be referred to?

**Hugh - neuro-psychiatrist:** I would say a neuro-psychiatric team that includes a neuro-psychiatrist, neuro-psychologist and senior occupational therapist, but I would have to admit to certain biases...

**Patrick - OT:** You mentioned OTs, that's fairly unbiased :-)

**Kate:** What kind of assessments would they do and are there many such teams around? Is this different from the work the neuro rehab team did with me three years ago when given MS diagnosis?

---

**Sam:** I sometimes find trying to struggle on with some things more frustrating than rewarding when my symptoms are bad. It's standing in the shop forgetting why I came, or getting to the counter and not remembering the name of the thing I want. Or not knowing the right word - I feel so daft and foolish

**Dawn - Psychologist:** Not knowing the right word is usually much more obvious to the person with MS than to the people around them

**Ron:** Does that include spelling errors all the time?

**Patrick - OT:** None of us are immune to that

**Ron:** I don't know if it is my spelling or typing now as I rarely write anything with pen and paper

**Sam:** It does dent your confidence terribly when it happens. I kept a notebook for a while but then kept forgetting to take it with me!!

**Patrick - OT:** Use a loop to hold the note book to your trousers. Simple but effective. Or, if you're a gadget guy, try a PDA (electronic notebook) or the memo function on a mobile phone.

---

**Patti:** I always understood, from my own research and my neurologist, that lesions do not correlate to disability

**Ron:** I just had this discussion with someone who is MS related who thinks a neurologist is of no use after a diagnosis is made and sees no reason for any further MRI scans

**Hugh - neuro-psychiatrist:** An MRI might give you an idea about lesion location and amount and you could try and tie this in with the clinical picture to create a story that explains how you are

**Dawn - Psychologist:** Actually there is lots of evidence that lesion load on MRI does correlate moderately significantly with both physical and cognitive function

**Patti:** I asked for a repeat MRI - and I got one. I wanted to see if the MS diet I am on was keeping new lesions at bay. Seems like it is making a real contribution - so I am sticking with it.

---

**Patricia:** Does MS affect short term memory or is it a convenient excuse?

**Patrick - OT:** It can do, Patricia, but so do other things

**Dawn - Psychologist:** Short term memory is one of the cognitive functions most likely to be affected by MS

**Sandy - Psychiatrist:** Although short term memory loss is common in MS, sometimes others don't understand and can suggest you are trying it on. But it is helpful for partners and family to understand that invisible symptoms like fatigue and memory problems can be common and distressing for people with MS.

**Pippin:** Can I work with cognitive problems?

**Dawn - Psychologist:** Do you mean work as in continue your current employment?

**Patrick - OT:** It depends both what the job is and what your cognitive difficulties are

**Pippin:** I stopped because of severe attack. I could not read words, time or music

**Patricia:** I have just lost my job because I cannot remember everything I do

**Dawn - Psychologist:** what happened, did you get medical retirement?

**Patricia:** No. I worked for a small private dental practice and I resigned because I could not retain everything they thought I should.

**Dawn - Psychologist:** It might be worth going to a citizen's advice bureau to see if you can open the case with work again.

**Patricia:** Oh! Thanks very much for the advice - I will pay a visit to the CAB

**Patrick - OT:** Also try the Jobcentre Plus system to look for work

**Patricia:** I should say that I resigned just before my probationary period was up. But it is all very demoralising. I do get very tired.

**Dawn - Psychologist:** The thing is that MS cognitive problems probably constitute a legal 'disability'. Work should have helped. If they couldn't, you should get extra benefits.

**Patrick - OT:** MS, from the diagnosis, is covered under the Disability Discrimination Act and it now applies to even small employers.

**Dawn - Psychologist:** Most jobcentres have some one to help with what are unkindly called disability issues. Seek them out.

**Patricia:** Thank you very much for the advice. I will persevere!

**Patti:** Surely there are some jobs that are dangerous to continue in, like operating complicated machinery or if you are responsible for administering drugs or treatment

**Ron:** There must be many jobs that are unsafe with MS - it can take on so many different scenarios

**Dawn - Psychologist:** For most jobs, unless there is physical risk eg balance problems for a scaffolder, there is usually no danger continuing working

**Patrick - OT:** Again it is important that the person has access to assessment to identify what someone can keep doing

**Patti:** What is the employer's liability then?

**Patrick - OT:** It comes down to something called 'reasonable adjustment', which include cognitive problems

**Patti:** How about me being in charge of kids? Is my employer obliged to put an assistant in the classroom if I can't cope?

**Patrick - OT:** Probably

**Patricia:** I was asked to administer some drugs which I did not like doing and am sure I should not have been doing.

**Dawn - Psychologist:** Anyone who feels they are being asked to act dangerously or irresponsibly at work - whether they have MS or not - has a duty to raise it with their employer

**Ron:** Try that with the merchant navy and a person would be fored, no question.

**Dawn - Psychologist:** I have personally represented members of the armed forces with neurologically-based cognitive problems and have usually seen justice done

**Ron:** My own experiences are not good with telling employers and I would tend to keep quiet about it unless I had to tell them now

**Dawn - Psychologist:** Of course you are the best judge of your personal circumstances, Ron. But if the time comes when you have to start negotiating with your employer, this info on legal rights may be helpful. Also I think the merchant navy union is very strong. You could always contact John Prescott! Never underestimate the power of embarrassing a politician!

**Ron:** Thanks, Dawn

**Simon – MS Trust:** As Patrick said, people with MS are covered by the Disability Discrimination Act - from the moment of diagnosis. Under this, employers must make reasonable adjustments, which may mean equipment, work schedules or reallocation to other suitable employment. There is a good brief guide to the legislation on the Disability Rights Commission website at [www.drc-gb.org](http://www.drc-gb.org).

**Patti:** Sounds like a pipe dream to me - I was ignored for four years after diagnosis

**Patrick - OT:** Patti, get an OT assessment or contact Access to Work via the Jobcentre. Access to Work can help the employer fund support

**Patti:** But that would effectively stop me from moving to another school or position

**Patrick - OT:** No, it is a portable agreement and you can employ the helper personally if necessary

**Patti:** So where an OT assessment? Will I wait another four years?

**Patrick - OT:** Badger either the local social services or try Access to Work first as they do rely on the person's self assessment

---

**Em:** I'm very insecure about future employment, I've been self-employed all my life until I was diagnosed. What next?

**Sandy - Psychiatrist:** One of the worst things about MS, Em, is the continuous insecurity, one thing after another. One loss after another can lead to anxiety, depression and loss of self image and self esteem

**Kate:** Em I was self employed, and really wished I had obtained better advice about MS much earlier as I think the responsibility of being the one to keep things going made things worse re MS.

**Patrick - OT:** If you are self employed can you not control the work somehow?

**Em:** You can control the workload, yes, but one needs to keep working. It's not easy to slow down, bills still need paying.

**Patti:** And I am the main breadwinner in the family

**Simon – MS Trust:** The Disability Law Service may be helpful if there is a problem. Their number is 0207 791 9800

---

**Simon - MS Trust:** Earlier in the session someone asked about how she went about getting a cognitive assessment. Any thoughts?

**Dawn - Psychologist:** It is probably worth going via a neurologist/psychiatrist with expertise in MS because he will know of a psychologist who knows about MS

**Kate:** I missed the reply to is the neuro-psychology team different to the neuro rehab team I saw three years ago and where do you find a neuro-psychology team?

**Hugh - neuro-psychiatrist:** Kate, the teams are not massively different, but a neuropsychiatry team may be more prepared to look at mental function in general

**Dawn - Psychologist:** The main thing is that you see an expert team with real expertise and knowledge of MS and the complex disability MS entails.

**Hugh - neuro-psychiatrist:** There are a few teams in the UK. Where are you from?

**Kate:** South west, Bristol

**Hugh - neuro-psychiatrist:** Have you tried the Burden Institute in Bristol (based at Frenchay Hospital)?

**Kate:** No where do I find out more about them

**Dawn - Psychologist:** Just give the names and hospitals to your GP

**Kate:** Thanks

**Simon - MS Trust:** I think we'll wrap it up there. Thanks to all the experts - Dawn, Hugh, Sandy, Patrick and Judy earlier in the day. And thanks to everyone for their questions and contributions to the session.