

Cognition

Chatroom

28 April 2009

www.mstrust.org.uk

Cognition

28 April 2009 - 10am to 7pm

- **Dawn Langdon** - *neuropsychologist*
- **Terri Johns** - *neurology nurse*
- **Patrick Carroll** - *MS specialist occupational therapist*
- **Anita Rose** - *specialist psychologist*
- **Jeffrey Gingold** - *advocate and author*

This chatroom is an open forum and so the views expressed by participants are their own and are not necessarily those of the MS Trust.

A list of publications and resources mentioned during the chatroom is at the end of the transcript

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

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Simon - MS Trust: Welcome to the chatroom on cognition problems

Dawn - neuropsychologist: The reason we are having this chatroom today is to mark the launch of StayingSmart, the MS Trust's cognition website tool. The address is www.stayingsmart.org.uk. Has anyone had a chance to look at it?

Laura: I've been on the www.stayingsmart.org.uk site and thought it was good. I tend to have problems saying things that are on the tip of my tongue.

Lynn - MS Trust: There are some tips and tricks on StayingSmart, I wonder if you find anything particularly helpful?

Laura: The tips and tricks I found are good, and just the general information.

Scoobs: I've just had a look at www.stayingsmart.org.uk and found my perfect gift... for MYSELF. A pen with post-its in it. Now where is my credit card!

Caroline: It is possible very temporarily to be unable to do something because something (method recognition) slips, eg standing on top stair wondering what to do next or how to write! Mad?

Dawn - neuropsychologist: Caroline, could you tell us a bit more about your experiences?

Scoobs: I struggle to remember 'things' often, but I feel I always have, I tend to be surrounded by post-it notes! I have a pad next to the bed and often wake up and write a note, otherwise I feel I don't sleep properly wondering if I will remember whatever it is the next day!

Claire: I really struggle when I need to read something. I get to the end and can't remember a single thing! It puts me off and makes me feel really stupid!

Nikky: Hi Dawn, could you explain what the links are between where there are plaques identified by MRI in the brain and the effect they have on cognition? And also if there is a correlation between the density of plaques and the severity of cognition impairment?

Dawn - neuropsychologist: Brain plaques, or lesions as they are sometimes called, can come and go, come back, get bigger or smaller. But over time, eventually they start to stay and gradually accumulate. They are signs of damage in the central nervous system (brain and spine). There are a few people with MS whose experiences have been recorded in scientific journals, who have experienced a big plaque that brought a specific cognitive deficit with it, and when the plaque went away, so did that cognitive deficit. But they are very unusual. Most plaques are relatively small. In fact, the amount of plaques is only slightly related to cognitive problems. This is because the brain can often overcome a plaque's effects by re-routing information. But there is quite a lot of tiny, microscopic damage to nerve fibres and their supports, and this has more effect on cognitive problems. It is a bit like the difference between Birmingham Bullring road system being closed (awkward but avoidable) and bad holes in the road all over the UK motorway system (unavoidable).

Simon - MS Trust: How do cognitive symptoms affect you?

Nikky: I really struggle to concentrate, do more than one thing at once, find words, remember what I was doing, and retain information. I've had a cognitive assessment as I couldn't do my work anymore and I have defective memory functions, (verbal, immediate and delayed memory), verbal recognition memory, defective information processing, defective attention and concentration and low average working memory.

Dawn - neuropsychologist: It is good that you had an assessment. Once you knew what wasn't working so well, were you given any advice on how to make things better?

Nikky: No, just the diagnosis then I was ill health retired. Do you know if there is any way of getting this help, on the NHS?

Dawn - neuropsychologist: Help with managing cognitive problems is available on the NHS, but you would need to go to a specialist centre (see map of MS services). You might try some self-management, for example looking at the StayingSmart website that the MST has developed (www.StayingSmart.org.uk). It includes helpful information and lists of books, DVDs and other websites you might find useful.

Laura: I tend to struggle at work - has anyone changed their working hours/cut down to part time?

Nikky: Me too, Laura, and I've found it one of the hardest things about MS to come to terms with. Somehow it felt that my identity has been changed as it really has affected my confidence. The thing I'm working on most is trying not to panic when I can't find the words - to try and talk round it till my brain catches up with me! Oh and trying not to give up and instead say nothing at all, when people jump in and finish my sentences!

Laura: Yes that's how I feel, Nikky, annoying when you are trying to think of the word and can't get there!

Dawn - neuropsychologist: Nikky, you are quite right to try not to panic. In fact stress, anxiety or getting tense can make it HARDER to think of the word you want. Sometimes it helps to use another word, or just say I'll come back to that. Usually other people don't notice you're getting stuck on words as much as you do, if that helps.

Lynne: Nikky, I understand exactly what you are saying. My short term memory is something that I have a lot of problems with. One problem is that when people are asking me questions I start going err, umm, err and then they will ask me another question before I have answered the previous one. Then I get the impression that who ever it is I am talking to get a bit impatient with all my umm-ing and arr-ing and there is frustration on both sides.

Scoobs: I'm now self employed, I started off working a three day week, but I've built this up to a five day week again. I'm very lucky that if I'm feeling particularly unwell I can take time off at very short notice.

Laura: I find it difficult to take anytime off that I may need and I feel guilty.

Scoobs: I quite often use the wrong words, using words that sound similar to what I actually mean. It is a little upsetting when people correct me, but I don't take anything personal and I find that keeps me sane in many areas of life! I quickly accepted that either in work or play I have to pull in the reins now and again. I haven't stopped doing anything. I just know when to rest up. It's very important for our wellbeing and you really must not feel guilty for taking time out (easier said than done I know).

Samir: It is hard to remember to say things and also to recall information I think?

Dawn - neuropsychologist: Lots of people with MS say that they find it hard at times to recall things. Have you found anything that helps with this that would help other people?

Samir: I think that writing out what you are going to say before hand, even if in note form, really does help.

Terri - neurology nurse: Laura, does your employer know you have MS?

Laura: Yes my employer does know. But because I'm not the sort of person that moans all the time - I will suffer in silence so no one at work knows what I'm going through. I was diagnosed last year in September 2008 so still trying to deal with it all.

Terri - neurology nurse: This is still very new for you so don't beat yourself up about it. Disclosing you have MS takes courage, so well done for that. Over time risk-taking will seem safer. Do you have a colleague or union rep. that could be with you when negotiating flexi time?

Laura: Yes it is still new to me so still trying to sort myself out. I don't think I have anyone at work that would help with flexi hours, although I have managed to change my hours to 8-4pm. I was struggling about 3/4pm as I was so tired, and I also work from home on Wednesdays which helps.

Lola: Laura, I went part time for a while when I was really ill and it worked well. When I went full time again the work load piled right back up and I was in a worse situation, so they appeared to have learned nothing. I'm still thinking of what to do.

In the past I worked for a few weeks part time hours and this did not work at all, as my employer expected me to do the same amount of work in reduced amount of time. I guess it's all about the supportive and understanding nature of your employer. I communicated well with them and they did with me, they just didn't act on what they were saying - empty words. If your employer is understanding I would say it is a good thing, as it will allow you to be independent and still get the rest you need to carry on your work and home life to the full. Hope that's useful for you.

Ladidi: Before I was diagnosed I started a new job and got the sack because I could not remember anything I was told. Now I have problems remembering things I have been told, I do write them down but often cannot remember where I wrote them so I bluff my way through

Dawn - neuropsychologist: I am sorry to hear about the problems you had with your job. There are some things you can do to help you keep track of what you hear and of the notes you make. Have you ever had any advice about how to remember things?

Samir: It is hard to write things down, especially in a conversation, how do you know how a conversation will flow? I usually work off the other person's words. One little word can bring back my memory.

Scoobs: I tend to make a joke about myself too! I often forget what I've told someone or they have said to me, I have to write everything in my diary. If I forget something I joke "oh sorry you know I have a terrible memory"

Laura: That's out of order to be sacked!

Julie: Good morning. I'm not sure whether I'm 'typical' or not. I've been diagnosed since 2000, I didn't have much confidence before and I now find it very difficult to do anything on my own. I am now resenting the very people who try to help me. I feel trapped. I can walk but often trip. I joined a camera club but I had to take my friend with me for support. I just want to be myself without an 'also' with me. I think the world of my friend but I'm so frustrated and I think eventually it will end our friendship, am I just being totally selfish?

Leonie: One of the things I really struggle with now I'm turned 40 is whenever I try to explain my cognitive problems to friends and relatives they say "oh - I get that as well - it's not your MS it's your age/hormones." I know they are only trying to normalise things but sometimes it REALLY irritates me. I have to choose who I discuss that sort of thing with. I also find I struggle if I spend too much time with manic people who have loads of energy - it can be exhausting. Some friendships have fallen by the wayside because of this. But through MS I have also made some fantastic new friendships.

Leonie: Just wanted to say that I'm glad the MS Trust are having a chatroom about this issue. I wish I'd known more about cognitive problems when I was first diagnosed nine years ago. I was a senior manager and my increasing inability to function in an open plan office was met by misunderstanding and even hostility by those who worked for me. By the time I had to finish work two years later my self esteem was in my boots and I had sunk into depression. It has taken a long time to build myself back up but I'm getting there. I now understand more about cognitive issues and fatigue, and am able to work around them - but I'll never be able to earn the salary I was once on and I'm only in my early forties. I now know MS is covered by the Disability Discrimination Act but do you think it is possible for someone who works at a senior level in a cognitively challenging job to be able to continue in post with MS?

Dawn - neuropsychologist: There are special people who work with people with MS to help them make the most of employment opportunities, including minimising the impact of cognitive problems. Usually they are occupational therapists. You could find your nearest occupational therapist who specialises in MS from the map of MS centres. Simon, can you give us the link?

Simon - MS Trust: The map of MS services can be found at www.mstrust.org.uk/information/services/. Choose occupational therapists from

the drop down menu at the top or the key top the left of the map. The map is continually being added to, so if you know of services that aren't covered, please let us know

Samir: My OT is a member of my local council, she comes to see me on a regular basis. You could contact your council for an OT?

Nikky: From my experience, it's really important to recognise where your difficulties are, then to get some help finding new ways of doing things. That's what I've found hard to find, the help. Has anyone had any help from clinical psychologist with working on finding new ways of doing things, new ways of using your brain?

Simon - MS Trust: Later in the day we will have an occupational therapist in the room. Patrick will be online from 2pm through to the end of the session at 7.

Leonie: I had a full neuro-psychological assessment and found it so reassuring to know that my problems weren't imagined but typical of MS. If only I had known that at diagnosis it would have saved my so much anxiety. My employer and colleagues knew I had MS but when I asked people at work if they would write things down rather than firing things at me they just thought I was being moody. There is a lot of work to be done in raising awareness of cognitive issues. On the plus side - although my mathematical and processing brain are defunct I have discovered a creative side to me I didn't know I had and it is opening so many new doors for me.

Lynn - MS Trust: I really agree about the importance of raising awareness of cognitive issues and we do hope that StayingSmart can help us to do this.

Chloe: How much does depression contribute to the loss of concentration and being able to find the correct word?

Dawn - neuropsychologist: We know from research that depression affects cognitive tasks that need a lot of processing, like mental arithmetic. It is possible to get treatment for depression.

Terri - neurology nurse: Depression has a huge impact on poor memory, concentration and apathy. Have you got good support networks?

Chloe: Yes, I have some support, but it difficult to know whether it's as a result of MS or depression that 'words fail me'. Is there a clinical test that can determine which is which?

Dawn - neuropsychologist: Yes, a specialist centre ought to be able to assess a person and advise whether depression, or cognitive problems, or both are involved. They can then offer treatment and management advice. I would urge anyone who is experiencing mood problems to consider getting professional input. You might be offered antidepressant tablets, or you might be offered a talking therapy called Cognitive Behavioural Therapy which can change your outlook.

Leonie: I have found Cognitive Behavioural Therapy really helpful in developing new thinking strategies and breaking negative patterns - but you have to go into it with an open mind and not be too cynical. Unfortunately despite a referral from my neuro-psychologist I had to pay privately for it. I am currently contributing to

the development of free on-line computerised CBT package available through the NHS to make it more appropriate to those living with chronic illness who also suffer from anxiety and depression. I'm really excited about it and think it will be a really useful tool for people with MS.

Dawn - neuropsychologist: I hope that your experience will encourage others to try this - hopefully not having to go privately! The computerised package does sound a great way forward. When will it be ready - do you know?

Lynn - MS Trust: Leonie it would be really interesting to know about your experience of cognitive behavioural therapy and the CBT package you are contributing to.

Leonie: The trial is currently in phase 2. I am working with the software developers on the script following the results from the pilot. As usual with these things it is hard to pin down timescales and then it will be a case of getting the word out to GPs, neurologists and MS nurses. Optimistically another 18 months.

Dawn - neuropsychologist: It is really great of you to put your time and effort into help develop this computer package.

Leonie: I have to sign off now. Just want to say that for me information is the key to coping with cognitive problems - although it doesn't make the symptoms go, it takes the fear of the unknown away. We live life so fast these days that in a converse way having to stop and think about things one at a time really helps me to appreciate the little things in life.

AG: Re: CBT - the University of Southampton is currently recruiting people to help with the development of an online CBT self help programme to help with fatigue.

Lynn - MS Trust: The study can be accessed directly from the University of Southampton website - <https://octopussy.ecs.soton.ac.uk/MSInvigor8/sections/introduction/welcome.php>

Samir: Do depression and MS come hand in hand? Most if not all the people with MS that I know are on antidepressants and sleeping tablets?

Scoobs: I'm not on antidepressants or sleeping tablets, or am I in the minority?

Samir: That is weird that you are not on sleeping tablets Scoobs. Do you not find yourself waking up at night and thinking about your challenges and hardships?

Scoobs: No not at all. I do usually remember things I need to do as I'm dozing, which is why I note them down, but once I've done that I sleep really soundly.

Laura: I'm not on them either, however I have been taking some sleeping drops which are from flower essence! They work!

Scoobs: Excellent, nice to know I'm not alone!

Samir: I am on Mirtazapine, sleeping pills and antidepressants all in one. I need them in order to get a good night's sleep, but still I suffer from memory problems!

Jan: Hi, I feel really stupid when talking to anyone, face to face or on the phone - I just can't remember the word/words I need. I also find it hard to concentrate when people talk to me, I seem to go off to my own world (I just stare so I have been told). This happens a lot. It's like a blank spell. One more thing is, any background noise stops me hearing what I am trying to listen to. When I try to read, write, watch television, my eyes jump. Well that was rather a lot but only a few of my worries but any help would be brilliant. Thanks.

Dawn - neuropsychologist: The problem with your eyes jumping may have a solution, you need to check with your neurologist. There are things you can do to improve concentration, which include minimising background distractions and "pacing" high concentration tasks. Have you tried doing anything to improve your concentration?

Nikky: Do the professionals rate any kind of computer type programme like brain training, mind gym? Is it possible to overcome the damaged areas in the brain caused by MS, by training the brain to use new pathways, kind of detouring the damaged areas?

Scoobs: I must admit I have Brain Training on my Wii, not sure if it's helping though!

Dawn - neuropsychologist: There isn't much research about using computers to improve cognitive functions in MS. What there is suggests that programmes that are carefully tuned to start at just the right level of difficulty for each person work best. Also programmes that get easier or harder, depending how well the person doing the training is performing.

Chinarose: I do Arrow word puzzles which help with concentration and there are no 'timers' to pit your wits against. I also have a little gadget that helps find the words for you. Like an electronic puzzle solver, so it gives you a bit of a boost if you get stuck.

Lynn - MS Trust: The gadget that finds words for you sounds useful - could you give us any more details?

Chinarose: It's called an Oxford Crossword Solver made by Seiko.

Jan: I don't know if it helps but I bought it to help! I have a Nintendo DS with some games like Scrabble, and a brick sort game called Puzzle League. I do have to have the sound off as I can't concentrate otherwise. As for phone calls, I seem to concentrate for the first five minutes and after that I seem to go off in to my own world and all of a sudden I come back and wonder what we were talking about.

Dawn - neuropsychologist: That sounds great. For business calls, you could make sure the important stuff gets talked about first

Scoobs: From a business sense I use emails all the time. I've set up access from my mobile and when I'm out and about on site, I email folk important things so I don't forget to do it.

Hellms: I have progressive MS and in the last 18 months I've gone from working librarian to retired (I hate that word 52 is too young to 'R'). I use Nintendo Wii for balance and a good laugh on the wobble board, Nintendo Gameboy when I'm needing mindless absorption and the DS. This is not an advert for Nin*****, it's what simply works for me. Please try and get MS better understood and people more aware. Shout louder.

Dawn - neuropsychologist: I am sorry to hear that you have such a tough time. It might be worth getting in touch with a specialist centre to see if there are any other employment options open for you.

Lynn - MS Trust: We are going to be working to raise awareness of cognitive difficulties in MS on World MS day in May - let me know if you would like to be involved info@mstrust.org.uk

Chinarose: I was diagnosed in 1998. I am heavily involved in my MS Society Branch. I used to sit at home all up until three years ago and decided to take the plunge and meet people with MS like me. We have a great laugh trying to communicate at times. Especially when working at our branch office. I feel much happier that I now know I am not the only one who talks gibberish at times.

Nikky: Talking gibberish at times can have a funny side. My partner and I have an agreement - if we can't find the word we want to use and we're too tired to try that hard, we just say the first thing that comes into our heads or talk round it. Amazingly we understand each other very well and giggle lots! Things like, "have you taken the dinner out of the er ...the oblong thing that's hot!" Sometime we just say the first word that comes into our head, which can be hilarious! I have MS, my partner blames it on the menopause :)

Chinarose: How's this for embarrassment then. My daughter was a bad car accident and had to be cut out of the vehicle. I mistakenly asked the firemen for sex! Help! What a mix up on words! What I meant to say was could I get in the car and help him!

Scoobs: I think you can be forgiven for being in a very stressful situation!

Chinarose: It caused a huge laugh and my daughter chilled out immediately while they released her. Thankfully she is much better, still undergoing treatment, but takes her mind off it by telling everybody my embarrassing tale.

Ladidi: Are there any vitamins/minerals that may help with my memory?

Chinarose: Somebody told me fish oils help. Don't know if that's true though.

Dawn - neuropsychologist: Unfortunately there is no evidence that any vitamins or minerals have a specific effect of improving memory. However, it is important to be well nourished and eat a healthy diet to maintain optimal health, especially if you have MS. It will give you the best chance of coping well with it.

Scoobs: I was told the same, healthy balanced diet, plenty of fruit and veg, fish oils. I think they referred to the Healthy Heart Diet.

Samir: There are also the Seven Seas multi vitamins to help with memory. My mum is always trying to get me to take them!

Chloe: Do you know if there is any evidence that taking tricyclic antidepressants are beneficial to those with MS?

Dawn - neuropsychologist: There is no research data about which drugs help depression specifically in MS. But all antidepressant drugs available on the NHS have been shown to improve depression in lots of big studies with other groups. Tricyclic antidepressants are one of those drugs.

Scoobs: It is appropriate to talk about fatigue today?

Samir: Fatigue is something that has been a HUGE problem for me! I hate it SO much! Makes exams even harder!

Nikky: I'm sure I'm not the only one who experiences a real link with fatigue and cognitive difficulties

Scoobs: Fatigue just makes me want to shut down! Like my batteries have completely run down, problem is a wee sleep doesn't always recharge them :-)

Laura: I suffer from fatigue badly but as I was only diagnosed seven months ago, I am still trying to figure it out!

Chloe: Do you have any warning when your fatigue is coming on? Any signs or sensations?

Scoobs: After my first relapse I was left with numbness in my right hand, this gets worse and feels very stiff then I just have to shut down for a while.

I was wondering if other found 'stocking up' on sleep and rest helps to prevent fatigue. I try to give myself easy days before busy days if that makes sense.

Jan: I feel for you. I too suffer badly with tiredness and my body just wants to shut down. I start yawning and yawning before it starts.

Nikky: I know what you mean. I try to 'stock up' and give myself easy days before busy days. I think it helps me. I try to do the same to help with situations that I know will be cognitively demanding too, like making important decisions or social get togethers.

Chloe: I find I trip more easily and my feet go completely freezing cold. I know I need to rest when this happens. I also force myself to sit/rest for an hour each day regularly between 2-3pm. People know I do this and tend not to contact me at this time which gives me space for guilt free 'me' time. I also have Uthoffs which means if I get hot through exercise or just walking, my eyesight becomes very blurry. Does anyone else have this? And how do they cope?

Scoobs: I have to logoff now, but I will pop back in later. Thanks to those here just now for the ideas and thoughts shared

Lynn - MS Trust: Thank you for being part of the day, Scoobs. Just to let you know that Patrick Carroll, an occupational therapist, and Jeffrey Gingold, author of *Facing The Cognitive Challenges Of Multiple Sclerosis*, will be with us later this afternoon.

AG: I am known at work for having an incredible memory for facts/figures/details but every now and again I suddenly find I am living in a mental fog. I put things down and can't find them, I completely forget to do things after only a short period of time, I can't think straight. It really gets me down. This started again yesterday and though I make a joke of it in the office, really I just feel useless and want to walk out of work. Can anyone - professional or otherwise - offer any solutions?

Dawn - neuropsychologist: It sounds as if you are having a bit of a tough time and I am sorry to hear that you are feeling overwhelmed. You could start making some changes straight away. You could try:

- reducing the effects of fatigue by doing the hardest jobs when you feel best and "pacing" your work by varying tasks every so often and taking scheduled breaks.
- see if you can reduce distractions, which interfere with your concentration. Some people wear Walkman headphones to drown out office noise - even though they are not listening to any music!
- writing down what people say may help.
- but probably the most useful thing would be to get specialist help, so that you can have your situation fully assessed and then get advice and support on how to make work better for you.

Terri - neurology nurse: This must be so frustrating for you. Do you try to plan little breaks in your day? Sometimes this helps. Make sure you keep your fluid (water) intake up too as this helps to keep focused.

Nikky: I know it's really hard when you know you are not firing on all cylinders like you normally do... ((hug))

Try and recognise when it's a slower/more difficult day. Plan in less, take more breaks if you can. BE KIND TO YOURSELF. I find when I try to be less frustrated with myself and allow myself to take the pressure off I function far more like my pre MS self.

One of the most enlightening things I found was when I reflected on how I spoke to myself in a fog situation (my word) I would never speak to ANYONE ELSE like that EVER! Watch how you speak to yourself. BE KIND TO YOURSELF

AG: I usually keep a TO DO list on my desk - but as typical of things right now my desk has got in such a mess I couldn't find it! I can't wear headphones as I am first pick up for the office phone - I work in a very busy school office and the start of term is always a bit 'manic'. Whilst I try and do the hardest jobs first, it is sometimes a matter of what is most urgent so I don't always have that luxury. At the moment even the simplest of jobs seems too much for me to keep on top of and that's when it really starts to get me down. I am seeing MS specialist nurse soon so will mention it to her.

Chinarose: I sympathise with you. My symptoms are exactly like yours. It used to drive me mad and made me feel like an idiot. The fog comes on you and it's

like a block for everything. I have found to use my method above, slow right down, plenty of fluids and also sugar levels are important too. I was told by my GP I have low blood pressure and sugar levels which all contribute too.

Chinarose: I find that producing a tabled doc on my laptop with 4(ish) columns helps as I can write things down clearly instead of scribbling all over paper in note form. I can use this to develop a strategic plan of order for things.

eg

Column 1 shopping on Saturday arrange lift /care etc

Column 2 list of items I will need, shopping bags, wheelchair, purse, cards etc.

Column 3 shopping list

Column 4 pick up keys, handbag etc.

I then stick it in a plastic folder I have on my front door ready for the trip and tick off when the job is done.

It really helps me.

I also believe in everything in its own place.

Terri - neurology nurse: What a fabulous idea, thanks for sharing your plan. I'm sure other will find this really useful.

Laura: That's a good idea, especially if you feel it works. I may try that!

Chinarose: It works for so many different things for me. They are posted all over the house! It's my only way of surviving memory loss at the moment.

Samir: My mum blames MS on my exam stress. I was diagnosed shortly after my final degree exams and Mum thinks that the stress caused the MS. I tried explaining to her that a) I have MS symptoms pre-dating that time and b) there are plenty of others with MS who have not had to take exams. Stress does induce symptoms but is not the cause of MS!

MS was really hard for me to come to terms with, I was originally told by a doctor that it was impossible for Asian people to get it, after that time I would always convince myself whenever I had a relapse that it was just an old football injury, it is only now with it having gotten worse that I admit to myself, after several MRI scans that I do in fact have it!

Jan: Can you help with this? I have been having strange feelings blank/missing/lost times. To give an instance of this (and this has happened many times), many times I have been talking to my daughter and the next thing I know, she is gone and I don't remember her going or how the conversation ended or if it did. I seem to have lost time, in fact blanked out.

This probably sounds strange but maybe the following will help (as I know it did with me). My husband and I watched Law and Order a few nights ago. When it finished I look at my husband and said "Well it can't be the end - who done it?" He said I must have fallen asleep. I knew I hadn't. My husband re-wound the programme to the last part I remembered and I was shocked to see I had missed

a good three or four minutes. I just don't know what happened? I wrote to the people on my MS message site and most of them had had this.

Over the weekend I have also had a severe mega pain in my face - lower back jaw creeping forward to my chin. It only lasted a few seconds but I have never had pain like it

I talked to my daughter about these blank/lost times as she has never said anything so I didn't know if she noticed anything. I asked her if she had ever notice me go blank or stop in mid conversation. She said, "You do stop in mid conversation and you randomly start a conversation when you haven't said what about... "

"What do I do?"

"You just stare!"

"How much do I do it?"

"Loads, I don't take any notice of it now."

"How long is this since you noticed?"

"I don't know but it's ages"

"Longer than we lived here?" (that is six months)

"Yes"

This happens a few times a day and I even done it when the lady was trying to trim my hair, poor women! No wonder she was worried about me.

Dawn - neuropsychologist: This sounds like quite a complicated set of experiences and there many be several factors at work. It might be worth getting checked out by a professional.

Jan: I told my MS nurse about my blank spells and said she would let my doctor know. That was a while ago, so they can't think it is anything to worry about.

Dawn - neuropsychologist: OK, that sounds as if you have everything covered.

Scoobs: I often start talking to folk as if we are mid conversation, I'm not sure if this is because I am thinking about what I am going to say before I say it and skip the beginning.

Chinarose: Wow, this conversation business is making me feel almost normal! All my family swear they have told me things I can't recollect, and I have said things I have no knowledge of ten minutes later! I thought I was going nuts!

Dawn - neuropsychologist: Chinarose, your point about families not knowing/understanding about cognitive difficulties in MS is an important one. Usually, the more family and friends know, the better they are able to help and support you. Sometimes family and friends like to read information, sometimes just to talk about what you are experiencing. A lot of people would like to help

but don't really know how to, or what to do, or when. Does anyone here have good experiences of telling family and friends about cognitive problems?

Nikky: I have found it has taken a while to educate my close friends. Most of them give me the time and space to get those words out, but with strangers I find it much harder. Anyone have any stock phrases they say to people to help them understand the cognitive difficulties they are experiencing? It's so tempting to want to say "can you stop jumping in, butt out for a minute and I will get there"!

Dawn - neuropsychologist: It is good to hear that those close to you are able to understand that you need the time and space to just GET to that word. Strangers are always going to be harder to deal with - it is a new thing for them. You could try waving your hand to signal "STOP", when they seem about to jump in. But if they do butt in, it might be time to be gracious and smile your thanks. Men sometimes give me their seat on buses and trains and even though I want to say "I'm NOT that decrepit!" I feel the best response is to smile gratefully...

Chinarose: I just say "Excuse me, I just need time to get my brain into gear." However, it's one of those hidden symptoms that is difficult for other people to get their heads round. I also find flirting works well with men! (Not so full on with fireman though LOL!)

Jan: My Tesco delivery arrived one day and the driver asked me if I have a bad leg. I said no, I have MS. The driver's reply was "Oh yes that's arthritis". Not many people know about MS.

Chinarose: Sometimes it's not even worth trying to explain. I often just say I fell down the stairs. It's easier

Laura: My fiancé always knows what I mean when I can't get my words out - although I do need to work on him regarding more jobs about the house he could be doing!!

Chinarose: Get him trained now. Once you're married the jobs become 'a round tuit' - they never get done!

Nikky: Dawn, you are absolutely right - a lot of people would like to help. I've found telling my close friends the exact difficulties I experience with communicating has made a big difference - not least helping me to recognise who is actually a close friend!

It's tough explaining the changes that happen to you cognitively due to MS, especially when they have been gradual. People who have known you for a long time tend to think of you in the old days. But it's worth the effort. Close friends now know that I can't cope with cross conversations, and they give me a bit more floor space as it were. That's scary in itself sometimes! They also understand that when I'm quiet it's because I haven't got the energy to keep up with the quick pace of a conversation, not that I haven't got anything to say. So when I do try, they listen. Good friends do that for you :)

What has been great is that, having friends who are really aware of the difficulties allows me to try things out with them - to risk opening my mouth and struggling with the words. And in turn I realise that I don't have the same degree of difficulties communicating all the time. I have good moments! That was really important to realise, as it's a real temptation to start shutting down.

Chinarose: My hubby is the best. If I trip on those invisible lumps in the pavement 'he says, "You want to watch that step, it's dangerous". Now all the family follow suit!

Nikky: Got to go now. Thanks all. Keep educating people about MS's hidden cognitive difficulties. The more people around us understand, the easier its going to be for us to deal with :)

Ali: I've had MS for 13 years and I have noticed that I sometimes forget some names, such as my favourite actors and singers or old friends (classmates in school) and so on. If I think a lot I may finally remember them. Do you think there is a technique to improve my memory?

Josie: I've always had cognitive problems but didn't realise until I was diagnosed with MS. If I can't remember something when I'm talking, I start going through the letters of the alphabet. It seems to work if only to calm me down. When I go from one room to the other for something and I have forgotten what I went for I retrace my steps and go back and usually before I get back I have remembered! I used to get frustrated but don't anymore. People who know me understand.

Dawn - neuropsychologist: There are a number of things you can do to remember names. If there are a few names in particular that always stick, you can try having a picture in your mind that links the name to the face. The more unusual or novel the link, the better. So if you wanted to remember Cheryl Cole, you could think of her in an elegant evening dress and high heels shovelling coal (coal/cole). That picture, because it is so novel, will stick in your mind and cue 'Cole'. Do you think that is a trick you could use?

Terri - neurology nurse: I love your idea about Cheryl shovelling coal...I think I might use that myself!!

Ali: Thank you, Dawn, I'll try that technique.

Laura: My friends seem to have become very distance since I got diagnosed last September. I don't see them very often now - maybe that's not a bad thing as I don't need friends like that! At least I now know who my real friends are!

Terri - neurology nurse: You do find out who your true friends are. Sometimes those you least expect are there, and if they run a mile, then you didn't need them anyway! It's all about training other people up!

Samir: I agree with you, you really do find out who your friends are when you need them the most. People can and will stab you in the back!

Kathy: My eyes are bad and I see very poorly. I know that when I've certainly told someone I'm going to phone them at 4pm, they say I haven't. Now I know I have but that is just one instance - friends and even family do not understand. If I ask for nothing in my path to the loo, there is always a pair of shoes, a schoolbag, an obstacle of some sort. And third, why don't 'carers' care as much as they could and take endless weeks holiday and sickness. I cannot get a care

manager for love nor money. And fourth (last gripe - although many more - why am I made to feel different and inferior? Not worthy of being a human being?

Jan: Hear hear, Kathy!

Josie: Kathy. Have you got access to an MS nurse? Mine is fab. I'm sure if you had one she /he would be able to help with a lot of your problems.

Dawn - neuropsychologist: I am so sorry that you are feeling overwhelmed by your MS and by not having enough support. It is horrible to feel different and inferior, as you say, and no one should be made to feel like that. Have you thought of asking your local MS specialist centre for a full assessment and then perhaps they can arrange more support for you?

Hellms: I am so sorry you feel this way, Kathy. It's one of the reasons that I don't get involved - it makes me sad. We are differently able. We are special and so very worthy. I am the most positive MS person I know - I try very hard very day to get on with things. It's not easy but what is the alternative? Mix with someone cheery or you be the cheery one.

Samir: I am the same. People think that they have the right to treat you as stupid just because you have a brain disease! I hate it so much but some people still do that.

Kathy: My hubby bought me some little gadget that helps your brain. But my fingers and eyes don't work. I know why, and try to understand that $2+2=4$. I do know that $4 \times 4=16$ and not 81 as they say I answered. If you were just given more time to write the answer, but then I know I would stay on level one forever.

Jacqueline: I wonder if anyone can give me advice. My husband was diagnosed with MS two years ago. His memory has become quite bad this past six months and there can be gaps in the day where he has just forgotten a whole hour. It has become really difficult to have a conversation with him as if it goes on too long he seems to forget what we are talking about. He has never mentioned this to me and I'm sure he thinks his memory is fine. How do I approach the subject with him - or do I just not mention it? I don't want him to think I'm adding this to the list of symptoms he's already struggling to come to terms with. But I'm really worried he has an accident as a result of it as he's still trying to work (he's self employed) and is still driving.

Dawn - neuropsychologist: You must be feeling very worried and I can tell you love your husband very much. It is a bit difficult to tell over a chatroom whether you husband might be at risk from a driving accident. It is possible to get an assessment of driving safety. The contact info is at the back of the MST cognition factsheet - perhaps Simon or Lynn could find it for us.

Simon - MS Trust: There are a couple of links that may be helpful. There are a few links in the [Driving and Transport section of the Living With MS pages](#). The mobility centres that can give advice on driving are also shown on the [map of MS services](#).

Finally, there is the [MS Trust's cognition factsheet](#).

Dawn - neuropsychologist: You say that you don't think your husband realises that he has trouble keeping track of conversations. Some people with MS don't

seem to notice their cognitive difficulties. It might be worth trying to raise the issue - he may have noticed some blocks in conversation or other cognitive difficulties. We can all understand his wish to carry on working, but if the time comes when he needs to change his work, I am sure that his having had conversations with you about the difficulties and being assured of your love and support, will make any changes easier to bear and manage. What do you think?

Jacqueline: He is a farrier (he puts shoes on horses) and so needs to drive to work. He is already very depressed and I think if I mentioned stopping him driving it would tip him over the edge. We have five kids (the youngest just three months) so I'm not working at the minute. For him to give up work would cause huge financial problems. I know his and everyone else's safety comes first so I suppose I'm just going to have to bring the subject up and hope he reacts sensibly.

Dawn - neuropsychologist: I can see you are in a sensitive situation. It might be worth thinking about getting the depression assessed and, if necessary, treated. Possibly you could get an assessment from your local specialist MS centre. They could help you broach these issues and may identify other factors that could be better managed. It is better to try to get help with things before a crisis precipitates your seeking help. Having said that, for many people with MS, it is as crisis or an accident that brings them into contact with the right services. Do you have any support yourself?

Simon - MS Trust: It may be less daunting if you can explore possible solutions to the driving problem and discuss these with your husband. This may be an area where an occupational therapist might be able to offer some help. There will be an MS specialist OT online from 2pm today if you are able to stay here that long. We are also running another chatroom on Thursday for partners of people with MS. If you are free then, you might want to drop into that session and see if anyone has had similar experiences.

Jacqueline: Dawn, thank you for your answer. He is on anti-depressants. He has an allocated MS nurse - but as we are both always there when we see her I never have a chance to ask her about the things that I'm noticing and I don't like to go behind his back. He's really fragile at the moment and is struggling to come to terms with his diagnosis.

Claire: My thinking and speech seems to get worse if I am busy or being quite active at that moment. If I am sitting down I can talk quite lucidly but if I am up and 'doing', it all gradually starts to build up. Because it comes and goes, I'm sure people think I'm putting it on at times - I know I can sound really daft and laugh myself sometimes at some of the things that pop out of my mouth or when the fog rolls in! Concentration is the worst and unable to get things done, people think I am lazy, but I just get 'stuck' in my head and can't get things organised. It's so hard, other people's reactions.

I would like to know how to explain to people that I am not stupid, despite what it appears! I am an intelligent woman and the fact that my words don't come out right or I lose track of a conversation and constantly lose my keys is just surface stuff. I am still in here somewhere! Are there any tricks for remembering names? I find this very embarrassing.

Dawn - neuropsychologist: Some people find it helpful to explain 'MS fog' as a telephone exchange with some faulty wiring. Most people can see that some

messages wouldn't get through and some people would get wrong numbers. This is a bit like what happens when you get stuck on a word, or say the wrong word.

Hellms: The more we worry about cognitive abilities the worse they get. Chill, try not to stress.

Claire: Luckily I am an artist so people expect me to be a bit vague and drifty. I'm interested in understanding why the cognitive problems can vary so much from day to day, hour to hour? The unpredictability is sometimes the hardest bit.

Is there proof that environmental issues have an impact or is it just down to whatever our nerve paths are choosing themselves at that moment?

Dawn - neuropsychologist: The variability of cognitive problems is probably the result of the disease process and the accompanying inflammation varying. There are also effects of fatigue, mood, heat, medication, infections. Can you explain "environmental issues" for me?

Claire: By environmental issues I mean I find I'm worse in busy places, almost as if there is lots of visual information to take in and it becomes too much. Plus hot weather, stresses in life - all things that are happening to you rather than within you. Does that make sense?

Dawn - neuropsychologist: Many people with MS find it hard to filter out extra noise, information or words that they don't need to think about. This distractibility can be exhausting and uses up precious energy and processing that could be better used elsewhere. Simple adjustments can help some people - like moving your desk at work to a quiet corner, rather than the middle of a room; or choosing a quieter side table in a restaurant, so that you can enjoy your table's conversation. You may be able to avoid busy places, for example by shopping in quieter streets or at less busy times.

Liz: I was diagnosed with MS 16 years ago, and no one told me about the cognitive problems. I don't know whether that is good or bad! I still don't know whether to be reassured that it is 'only MS' and not that I am going mad, or to worry that it will get worse.

I have found the best thing for memory is a notebook and a diary, taken everywhere. Things written on scraps of paper are just lost. I explain to friends and work colleagues that if they don't see me write it down, I will forget it. Then if they say 'but we were supposed to be doing X today' I look at my diary, and if it isn't written down, I feel that I can't be blamed!

The general memory and word loss just has to be accepted. I always had a great memory, and now I haven't. Some people never had a good memory - who is better off? Hit 35 and everyone starts complaining about word loss! I am a university lecturer - I get into my stride and miss a word and just have to say 'sorry folks, I've lost the word', go back to my notes and start the next bit. Apparently it's one of my endearing qualities!

I hate constantly forgetting students' names - I feel like it's rude to them, but all I can do is explain. I have pictures of all of them above my desk to help.

I find concentrating in meetings to be the hardest task of all, because it's so difficult to take a break without appearing rude. I can cope for about 90 minutes,

and maybe a bit longer if I mainline coffee and biscuits, but afterwards I have to pay. If only we could have a sofa at work, and could take a little nap....That is something that would help AG I think.

Dawn - neuropsychologist: Thank you for all this advice. You work in education, as I do, and remembering students' names is a problem for all of us. So I am not sure it would be such a disaster for you.

Max: I have MS and now also epilepsy and my memory problems are awful. But the question I have is whether exercises like Sudoku or memory challenges can actually help in the long run, or whether the extra stress and intense frustration / anger with myself is going to do more harm than good. Anyone out there had any experience of this?

Dawn - neuropsychologist: I am sorry to hear that you have MS and epilepsy - that really is a double whammy. You might want to get a specialist assessment to make sure that your MS and epilepsy are being managed optimally - there are medication issues that could be reviewed.

Regarding computerised training of memory, there is not much research, but it seems that most effective programmes:

1. start at a level specially tailored to each person's own cognitive performance level, and
2. are responsive and flexible to each person's progress

Max: I am seeing specialist consultants for both MS and epilepsy and having my medication reviewed regularly to try and settle the epilepsy and get my driving licence back (oh what a joyous day that would be!). How do I find a) the person to carry out the "specialist assessment" you mention, and b) the computerised training?

Dawn - neuropsychologist: It sounds as if your specialists are still working to control the epilepsy. Once that happens, your memory and so on should improve. It is tough not being able to drive. Are you being seen at one of the specialist centres on the MS Map?

The computerised training is not available as far as I know as a treatment in the UK - can anyone else help with this? Otherwise using commercial products is your best option. Some memory training aids are listed on StayingSmart.

Simon - MS Trust: The links Dawn mentions are:

- [map of Mobility Services](#)
- [StayingSmart](#)

The links are listed at the end of the transcript

Karen: My memory and concentration is just not happening at all at the moment. Sometimes, I just think it's me, you know, life really. Having three kids and having your brain frazzled! I have to leave post it notes all over the place. I forget what day even month it is. I think it's pretty scary sometimes. I hadn't realised that MS could do this to me. Doesn't it mess up your life enough?

Lola: Indeed it does Karen. I can't concentrate lots of the time and I find watching a film or something on TV very difficult as I easily lose track of what's going on and who is related to whom etc. My daughter must be so fed up of me asking questions. Just as well we have Sky plus (and that's not an advert) as we have live pause and she we can stop and rewind etc.

Karen: Is it true that stress can make MS worse? I do worry about this. As you will probably agree, this life we lead is pretty darn stressful at times.

Lola: I use to think stress was the catch all excuse for many things, but I do now agree that stress can trigger things off. You may not always be aware that you are stressed, I'm certainly not, especially if you have three kids and a busy life like you say. I have a grown up daughter and work full time, but I get very tired and stressed at times. It took me a very long time to learn to be kind to myself and admit that I needed a break - even if it's just ten minutes on my own with a cup of tea, doing totally nothing, not even thinking, just letting my mind wander.

It can sometimes feel as though you are being selfish if you want/need time on your own, but really it isn't - I think it's quite the opposite. You want to stay well for yourself and those you love and care for. Take those ten minutes, as they may stop you being ill for a lot longer later on. That's my opinion anyway.

Lynn - MS Trust: The article in Open Door [Managing stress in multiple sclerosis](#) might be of interest. It looks at the links between stress and MS and has some tips for managing stress.

Amanda: I've just been reading all the entries and have remembered a bit of it!! There's a lot of useful advice there, thanks.

I have a thing that I use to remind me of events etc. I put reminders in my mobile. If it's a weekly reminder, when it beeps to remind me I'll edit it to go off a week later. It really works and I'm glad I do it - my library has missed out on lots of fines I haven't needed to pay!

Max: For anyone with fatigue problems, (most of us?) you may like me have heard the advice that a little exercise actually helps reduce fatigue, not increase it. I certainly find this. Anyone else?

Simon - MS Trust: And as you have mentioned fatigue and exercise (and increased fatigue can of course make cognitive symptoms worse), you may be interested in our book [Living With Fatigue](#)

Caroline: People talk about brain training gismos. What are they, please?

Lynn - MS Trust: Hi Caroline, I think people were suggesting here things like some of the Nintendo Wii or Sudoku. Dawn suggested earlier that there is not much research, but it seems that most effective programmes start at a level specially tailored to each person's own cognitive performance level, and are responsive and flexible to each person's progress

Caroline: I do cryptic crossword puzzles and Sudoku and Freecell ad infinitum. I think a Wii might be rather expensive!

Amanda: I agree, Wiis are expensive, but a DS is less so and it will fit into your handbag! There are quite a few 'mind games' on offer.

Caroline: I'll look on eBay for a DS (when I can tear myself away from this chatroom). Thank you.

Peter: I have a different slant on what has been said thus far. I like to attack problems, so I hope my experience might provide some hope to all sufferers out there. The story is long, but I truly feel it's worth sharing. I provide the solution to what helped me.

I was diagnosed with MS in 2005 after losing vision in one eye back in 2003 plus a few other symptoms.

The condition progressed to primary fatigue in year 3 lasting some 2.5 years, periodically debilitated me for an hour or so at a time.

I also suffered from paraesthesia that was quite mild but irritating, memory loss - particularly short term instant recall and clumsiness resulting from dysfunction in assessing distance and space. My mind would also 'dumb-out' when presented with a multitude of stimuli - eg noisy parties, loud music with high trebles, three noise sources confronting me at the same time etc. I could not hear two voices at the same time - my brain could not process the information.

I have around 35 lesions on brain and spine.

I have found that MS needs to be attacked back.

To this end, my research led me to a product on the market called EYE Q, available at Boots, and a high quality Vitamin B Complex which helps absorb the fatty acids in the EYE Q capsules more efficiently.

To be truly effective, I found cutting out saturated fat to about 10% of my daily intake allowed the blood to carry the nutrients in the vitamin B and EYE Q around the body efficiently.

I only consume around 7-10g per day saturated fat - I found being strict was essential to benefit from the supplements, so I cut out cheese, fatty meat, chocolate, biscuits, cakes sugar and full fat milk, cream etc.

I eat mayonnaise, taramasalata and Flora because, although high fat, they contain high omegas and are low in saturated fat. I eat fish regularly, preferably oily - also sashimi.

I only shop in butchers, bakers, fishmongers and organic grocers. If you think it's expensive, I actually found my shopping is around £15/week less than from my local Superstore - reason? I only buy what I need, and no prepared foods either (which are pricey). I also do not pick up little extras off the shelves and the big shops are not as cheap as they make us think! The saving has mostly funded the expensive treatments and supplements I take!

Finding quality suppliers means you cut out rubbish that fruit and veg are sprayed with, and fish and meat and pumped with to fatten the profits of the conglomerate. I also avoid tinned and prepared foods and do not do takeaways at all.

This regime has taken me some five years to perfect through a great deal of trial, error and discipline - the EYE Q and vitamin B are the only constants in my regime since 2004. I have lapsed on several occasions and symptoms came back EVERY TIME I did.

That was step 1

Step 2 occurred in 2008. After attending classes at the National Hospital in Queen Square, London, the concept of homoeopathy was introduced to me in 2006. After my PCT refused to fund referral to the Homeopathic Hospital (also in Queen Square) I undertook to find and pay for my own treatment.

There are loads of unregulated homoeopaths out there and after seeing four without success that ranged from quack to quackers(!), I was introduced to a fantastic homoeopath who I regard as important as my consultant now.

After finding the appropriate remedy for me (mine will not necessarily work for anyone else) I can safely say I encounter MS symptoms on the odd occasion and only after really pushing myself - I am not 'cured' - merely my body tolerance to MS symptoms has been extended before the old symptoms kick in. I have found everything is working again, memory/cognitive functions and including damaged motor functions.

Step 3 - Latterly I am attending anger management classes to assist me in the complete control of my nerves. The idea is, if I am calm and can control my nervous responses effectively, I put the minimum amount of undue strain on the central nervous system.

Conclusion. It all makes sense to me. I have attacked the damage physically with supplement and diet, I attacked the body imbalance with homoeopathy, and I am attacking anger from a mental perspective. Mind, Body and Soul.

I had my last appointment with a consultant last week and they have effectively stated in conclusion "If you need us, you know where we are. Otherwise we'll see you in a year's time".

My method might work for you to. I make no promises, but I am sure if your MS were attacked with the same gusto and desire to be rid of it as I have done, many of you will achieve improvement.

A very positive mind is required to defeat the helplessness and depression that MS makes us feel.

Simon - MS Trust: Thanks Peter - a positive approach to life (however this is achieved) can be a great help in tackling the obstacles that MS can present

Karen: I feel truly inspired! I feel angry/irritated like I have never felt before. Again, I had no idea that this would be related to MS. I don't think it has really sunk in if I am honest, even though I was diagnosed two years ago after the birth of my third boy. I am going to try homoeopathy and the omega fish oils. It is very easy to let MS get a hold of you and feel very low, but I am going to at least try and be stronger for longer! Thanks for a very inspirational post.

Peter: Thank you for your kind comments Karen. A gentle warning - you can be put off homoeopathy if you come across a poor consultant - it can be hit and miss and the problem with an unknown consultant, is that you may be seeing them for a few months before realising they have done nothing for you.

A good one should ask many questions about you and some very precise questions about symptoms you may have. It should almost feel like a therapy session rather than a visit to the doctor.

They should also find out what your constitutional remedy is as well as prescribe other remedies for acute symptoms. The constitutional remedy may take a few visits to work out for you as we are all so different. Someone claiming they have found yours in half an hour is probably a quack.

One universal remedy for most MS sufferers who struggle with fatigue is one single Arnica 30c (Boots do them) every time they get fatigued. There is a special way to take them, so do see a consultant first, but generally don't handle the pill and don't have anything 15 minutes before and after you take it.

Re supplements, diet is essential - if you have not cut out the stuff as I have stated, the supplements will not work as your blood cannot carry the lighter molecules of fatty acids whilst it transports larger and heavier saturated fat molecules in the stream, consequently the supplements are just ejected out of the body as waste. Apologies if I'm not medically savvy, but this is the way I have understood the process as a layman.

Once you sort the diet, the supplements should have an almost immediate impact and you may also find improvement, as some damaged areas of myelin are repaired by the supplements.

I am really confident my regime will work for others and cannot wait to hear some more good news stories. I feel fantastic for doing this and so will many people who have MS.

My mental attitude is, I DEAL with MS. I do not SUFFER from it - that also helps and is actually one of the biggest steps. I am positive in everything I do relating to MS - even when I relapse, because a relapse is something I allowed myself to slip back into.

I hope I do not offend anyone with my bold front on it all, and it's possible my regime works for me and no one else - but I doubt it. I am sure many will benefit.

Ellie: I saw Dr Clover at Tunbridge Wells Homeopathic Hospital when I was first diagnosed. I saw her three times and she is supposed to be, or was - this was years ago, top drawer, but nothing she gave, either advice or treatment made any difference at all, so I decided it was not for me

Geoff: It is important to feel as if you're doing something, isn't it. It's very easy to find yourself sitting there thinking 'poor me', but trying a few things can help combat that. OK, I've tried things that did nothing, and been tempted by things that were probably not good ideas - but I've been prepared to try and fail and feel it has helped me.

Lynn - MS Trust: Thanks for this Geoff, everyone is so different. Are there any things that worked well for you when dealing with any of the issues that have been discussed today?

Geoff: No it was more general things really. I've dabbled with diets and alternative things. Acupuncture and massage seemed to help, in the short term at least. FES is good. Cognition - still a little wobbly with memory and losing words at crucial moments

Simon - MS Trust: Patrick has now joined us to give an occupational therapists point of view. Does anyone have any questions for him?

Caroline: I have just been looking at the StayingSmart site. Good to see things collected together in one place.

Lynn - MS Trust: We also hope that people might like to share their ideas and experiences in StayingSmart - any tips or tricks that have really worked or gadgets that you have found particularly useful.

Max: Something I find has helped me remember where I have put an item, is when I put it down, I just look at it for a few seconds. I consciously 'photograph' the colours and shapes in my mind. It all seems to come back to me much easier that way. That is when I remember to do it...

CK: Can I just say that the StayingSmart website is looking very good. I am going to get some friends to look at it. It is easy to navigate and I think it will explain to them where I struggle in a way they'll find easy to understand (I find it hard to put into words!) Thank you, great job!

Patrick - OT: In my experience the more different ways someone uses to remember something the better their recall seems so writing, looking and using strategies all help

Samir: To help with memory I make what I have to remember into a short story, you can start it how you want but I usually start with "once upon a time there was..."

CK: I find it hard to organise myself. I regularly lose keys etc., tried having special place to keep them but I'm usually distracted as I'm coming in by my kids or something so never follow through the routine!

I write endless lists and work my way through them which does help me a lot. I muddle through most of the time but I find other people just don't 'get' it.

Are there any ideas out there how to improve concentration in busy places? I sometimes find shops, cinemas, pubs etc completely overwhelm me with too much going on. I don't want to avoid them really. I love these places, just want to know any tricks for keeping focus in a busy environment?

Patrick - OT: Could you give a specific example of what you loose concentration on in a busy environment?

CK: I find it hard to follow my companions' conversations and general just get a bit brain foggy. It feels like I'm over stimulated and can't separate noises. Not sure I'm explaining it very well! I just can't concentrate if there is a lot going on so it would make sense to go somewhere quieter again. Yet I want to still shop, go to the football etc.!

Bill: I get that - I can't shop at busy times with people and traffic and bustle. I need to go when the streets are quieter. Otherwise it just feels like my head is filling up and I can't think

Patrick - OT: You describe it very well, what is happening is the ability to filter, and ignore things is not working too well so your brain tries to process everything at once and gets overwhelmed. So it's not really your concentration that's impaired, more likely your ability to focus attention.

For pubs try one without music (if that's possible now-a-days?) otherwise the quietest part then sit with your back to the room and facing your friend, that way you cut out the extraneous visual stimulus too. If with a group get them to talk one at a time as much as possible. Even closing your eyes to listen can help.

CK: That makes sense, it is about focus. I find that when I'm walking around in these situations it helps me to look down at the floor, not to look around too much.

My doctor thought it was anxiety but it's not, I want to be there and I'm enjoying it but just struggle.

Bill: Thanks - that sounds helpful. Just getting away from the noise for a short while relieves the build up.

Patrick - OT: Although you'd need to be careful I have worked with someone with MS who used ear plugs when walking between places around town to reduce the overall stimulus load. He'd take them out in the shops. I say be careful because you won't hear cars very well so extra care crossing roads!

Patrick - OT: CK, try playing around with time, like how long you can feel comfortable and at what time of the day or even week. The trouble with MS is if you're tired then other things become difficult. So short periods like joining friends for an hour or less?

CK: Thank you, no one has ever understood what I meant before! Will try sitting with my back to the room, sounds like that will help. Thank you, not going mad after all!!

Patrick - OT: I think there is a lot of lay misunderstanding (and I include some doctors) about cognitive problems.

Simon - MS Trust: Look for the next issue of Open Door (our free, quarterly newsletter), which will come out in May. It includes an article from someone who had this type of problem at work - noise and distractions that meant she found concentration very difficult. She writes about the relatively small changes that she and her employers made to minimise the effects. If you don't get Open Door, you can join the mailing list at [Open Door page](#) of our website

CK: Patrick, do you think Arsenal will agree to play their home games at a time to suit me? :) Football crowds are a nightmare for me, too many people moving all over the place in a small area.

Patrick - OT: Hmm? I doubt it but do you watch from the stands or pitch side?

Max: Try a quieter game. Like Accrington Stanley.

CK: I sit quite close to the pitch. I'm thinking of giving it up as I do find the crowd difficult, noise, movement etc. More of a problem getting to and moving around inside the stadium rather than while actually watching the game. It is frustrating, I have gone since I was very young and don't want to stop but it seems to be becoming increasingly difficult to tolerate.

Patrick - OT: Well CK there are a number of strategies but they all involve compromise. You could try ear plugs when getting to the stadium and/or dark glasses (wrap around) to reduce visual stimuli but you may need a mate's arm to hold as a "guide". Otherwise abandon walking for the afternoon and get pushed in a wheelchair? It's as much about what you are prepared to do to "hold onto" the important bit of watching a live match. Thankfully Pompey have avoided the drop - I think!

Simon - MS Trust: CK - a number of clubs have improved their facilities for supporters with a disability. What Arsenal can offer and if it's relevant for you isn't that clear from their website, but you can find information at www.arsenal.com.

Mo: I am a single mum and have found cognitive problems are getting worse and it is scaring me. I am worried that I will make a mistake that will endanger my kids and someone will say I can't care for them. I forget to turn the oven and gas off sometimes when I'm cooking. No disasters yet but it is worrying me.

Patrick - OT: Hi Mo, have you got any support from social services at the moment?

CK: No, I have no support either. I'm not so bad and manage most of the time without too many problems. Just aware it is getting worse now. Scared to talk to people in SS for example in case they want to say I can't be safe for my kids. But don't want to put them at risk either obviously.

Patrick - OT: I think you are worrying unnecessarily and they will do everything they can to keep the children with you. There are quite a number of simple systems and alarms for gas and such like, your energy supplier or British gas should have an advisory service. Mostly the things they can offer are to help people with eyesight problems or generally elderly but that doesn't mean you couldn't benefit.

Sheila: Hello everyone, this is an interesting day. It seems that there are a lot of people who know the difficulties of cognitive impairment and the frustration and energy it takes to learn and deal with. I was a lecturer and now find that the mobility difficulties are not as bad as the cognitive difficulties as people cannot see the difficulty or the frustration.

I shut my eyes to speak so that I can see what I am saying and describe the picture. Sometimes if I don't filter out the background then my brain seems like a scrabble bag of letters.

I also use mind mapping to help me. Has anyone heard of this?

Bill: What is mind mapping?

Sheila: It is a way of connecting ideas into a simple diagram which can be expanded as need be but it is extremely useful as the thoughts can be random and so that helps MS where you cannot always keep a thought process going as another thought comes in and overwrites the first one and then you get lost. It is a more visual way of developing lists.

A mind map is a graphical way to represent ideas and concepts. It is a visual thinking tool that helps structuring information, helping you to better analyze, comprehend, synthesize, recall and generate new ideas. Just as in every great idea, its power lies in its simplicity.

The isolation that MS people feel because of the processing difficulties that hopefully will be better understood so that there would be help earlier in diagnosis so that people do not lose confidence as they feel that they have become stupid which is not the case.

Max: One of the big worries I have is that a lot of the cognitive symptoms that I experience sound similar to Alzheimer's. Is there a way to put my mind at rest over this?

Patrick - OT: Cognitive difficulties in MS are VERY different to Alzheimer's. In MS the person does not lose the concepts of orientation and self that happens with elderly patients. It is mostly memory/recall and focus attention that causes what are mostly comparatively minor problems

Max: Can you tell me what is meant by "concept of orientation and self"

Patrick - OT: Oops, slipped into jargon! Orientation is knowing who you are, where you are and what time it is. These are critical things to understanding oneself, like the building blocks of being 'you'. As I say these aren't lost in MS which is mostly processing of things around memory and recall.

Max: Many thanks for this. That really does relax me.

Patrick - OT: Glad it's helped, Max. Remember, dementia is very very different to the common cognitive difficulties that are seen in some people with MS

Richard: Like the chatroom. Recently diagnosed in September 2008 and overdid the exercise so off work.

Omega 3 oils good - reduce inflammation. Omega 6 oils (primrose oil) do the opposite but have been recommended for MS - any ideas if I should take it.

Kate: A few weeks ago The Food Programme on Radio 4 mentioned the 3 and 6 balance in the western diet and that too much 6 may be connected with

inflammatory conditions. The programme mentioned a book by Susan Allport 'Queen of Fats' (University of California Press, 2008). Seems to me one would need to know one's own omega 3 and 6 ratio before knowing if taking supplements would help.

Andy: LOL all Omega 3 oils do is make your brain bigger...not better. Oh and they make you smell like a herring

Richard: I have not told work about my situation. It is a huge company and currently wondering whether to tell them now or wait until I have more obvious cognitive issues - any guidance.

Samir: In line with the Disability Discrimination Act 2003 your employers are not allowed to discriminate against you on the grounds of disability. MS is one of the many disabilities recognised by the act

Richard: Thanks Samir. I suppose it's more the opportunities that I'd be overlooked for that would be the issue. The sickness database includes MS and I have little doubt they'd help out - eg laptop for home working etc.

Samir: Yes, but they can't discriminate against you on the grounds of MS so you should not miss out on anything! I really can't stress the point enough! MS is a hard disease to deal with, don't let it stand in your way and just get it off your shoulders and disclose it to your employers

Max: In my career, I experienced several redundancies - by coincidence (?) most shortly after the employer found out I had MS. That led me to ask myself if it had been wise to keep it a secret at the interview. An awful quandary to which I still have no answer.

Samir: I used to keep it secret at interview because I used to believe that I did not have it! Long story short, "honesty is the best policy"

Patrick - OT: Employment law is difficult to enforce as there are lots of subtle ways to get someone to leave. Even big employers can be very poor. Mostly it is about ignorance in that managers assume that someone can't do their job because they know so little about MS. If I can get employers to let me in to talk to them on behalf of the employee then understanding tends to improve the person's prospects

Samir: I agree it is hard to prove discrimination, but why live a lie?

Richard: Thanks for all for the advice. I'll speak with neurologist and my MS nurse about an OT to speak to the company.

Leonie: With the current changes to the benefits system, will cognitive issues be taken into account when decisions are being made about the long term unemployed with MS? Do the powers that be even know what MS is let alone all the different aspects of it when they put together a profile of what they consider to be someone's capabilities?

Patrick - OT: I think the real problem with any legislation is that its power is in the spirit rather than the case law. Sadly fighting a case is often too hard for

people as they are coping with a disability at the same time. Mostly managers are ignorant about both MS and the law.

Leonie: I agree. There is such a lot of work to be done to raise awareness of MS with the decision makers. Since I had to finish work, and with the help of disease modifying therapy, my MS has stabilised significantly. I do several different types of part time voluntary work when I am feeling up to it and am happy to, but the thought of running a home and family and once again having to commit to a paid job where I was expected to work set hours and perform consistently freaks me out after my past experiences. I don't think I could take that risk - but am I being too negative?

Patrick - OT: Negative? Absolutely not, I've worked with people who wanted to give up work as soon as they could and people who have hung on into their jobs way beyond the point I might have, BUT it is all about individual choice and priorities. There are no wrong decisions only misinformed ones. I would hope everyone has the opportunity to weigh up the pros and cons of their individual situation and then decide if they want to work or want to do other things.

Leonie: Thanks for that, Patrick. I wish I'd spoken to someone like you six years ago! My ex employer still doesn't have a clue what was happening to me and why I struggled the way I did. It made acceptance of my diagnosis so much harder. But that was in the past and I am now looking to the future - I am now a published author and have been shortlisted in a national short story competition. I'm off now for a rest before the kids get in from school.

Max: Leonie, one of the few risks I have taken in my life was to pack in my stressful career and retrain. I was able to make myself self-employed doing something I have always passionately enjoyed as a hobby. And it earns me a little. Not nearly as much as before, but I have never enjoyed working as much as now. I can honestly say that I am happier than I ever was. I work when I want, as hard as I want, and where I want.

I guess I am very lucky to be in a situation where this has been possible. But I am so glad I jumped at the chance. So I would say, don't force yourself to do things that you know may harm your MS even more.

Geoff: Is there a link between fatigue and fuzzy thinking or is that just a coincidence?

Patrick - OT: I doubt it is a coincidence in that pretty much everyone with MS says that if they are tired then all their other symptoms are more obvious to them. If you look at sleep deprivation experiments fatigue does quickly impact on cognitive function.

Sue: I was diagnosed with primary progressive MS in March 2008. I had also stopped smoking in June 07. I also began driving in June 08. I have a full time desk job too. I have subsequently gained 2½ stones. I have been trying hard to lose this and am not having any luck. I have been using a tried and trusted low-fat 1000-1200 calorie programme. Obviously I must be eating more than I am burning off but I find physical exercise very tiring. Can anyone help please? How many calories should I try?

Patrick - OT: The easy answer is to say eat less, mostly plants and move more. However balancing fatigue is a tricky act, my suggestion is talk to a qualified

dietician via your GP, they should help with a diet that provides energy and sufficient nutrients.

Andy: I have had a full psychological evaluation (three days) two years ago.

I have been having odd problems recently when halfway through I conversation I can't recall the person/ item/ event that I know I used to know.....does that make sense? Sometimes this creates a panic like response which makes the matter worse. Is this just old age or is it MS related?

Patrick - OT: I assume two years ago the evaluation didn't identify any significant problems? What you describe does make sense especially if you are distracted mid way through the sentence, and it may be something very minor that distracts you or even an internal thought. Sounds like you get stuck with a tip of the tongue knowing you should know what you want to say but just not getting hold of the word?

Andy: The evaluation found nothing wrong with me which was a surprise. My memory and recall were good, BUT I am aware I have an increasing problem. This has been changing more over the past 12 months. Brightly lit rooms with a lot of noise and a lot of primary colours cause a panic response, and the recall problems seems to make that worse.

Patrick - OT: Getting stressed will make it worse so having a breathing strategy or a way of 'taking five' may improve the recall?

Andy: As an example of the type of problem, there was a magazine at my brother in laws that had a full colour picture on the front page, I knew that I knew who the person was but couldn't remember. It was Jimi Hendrix

Patrick - OT: Your example is a recall problem and lots of people without MS get the same phenomena at times. The strategy I use is to slowly and steadily say the alphabet to myself and often when I get to the first letter of the name it triggers recall so "J" in the example you use. Another strategy is to describe the person and what they do to yourself and see if that links to the memory. It's not that you've forgotten the name but are struggling to recall it from your memory bank.

Andy: I will try the alphabet idea thanks.

Patrick - OT: I think you are describing a couple of overlapping difficulties. If you can't filter out stimuli then the overload will cause recall problems because your brain has too much to deal with. Have you tried tinted glasses if bright lights and colours trigger problems?

Andy: I use dark glasses most of the time when I am outside in the day. I find it helps me a lot. I have optic neuritis in my left eye which only sees in black and white and is down to about 30%

Patrick - OT: Perhaps a lighter tint for indoors?

Andy: I have had some recent problems where I lose time, is that typical of MS also?

Patrick - OT: Andy, can you describe "lose time" differently?

Andy: Yes by losing time, I used to have an almost inbuilt timer. I find myself nowadays losing track of the time. I have to set my telephone to remind to do basic things, such as get my son from the station, things like that.

Patrick - OT: Ah, remembering to do something (in the future) is called "prospective memory" and I'm afraid is one of the commonest things people with MS complain about. However alarms do prompt and once prompted people generally remember why they set the alarm

Andy: The important thing for me is to remember the alarm went off...LOL

Patrick - OT: Yes, too early and you might forget it's gone off, too late and you'll be racing to get there ;-)

Dave: My wife has a lot of cognitive difficulties as a result of her MS and has become much less aware of other people's feelings and her concentration span is often very short. Are there certain environmental factors that can make these symptoms worse such as depression, tiredness, etc?

Patrick - OT: Yes especially depression, which should be treated. Sometimes people become quite self centred around their own problems and struggle to see that the people around them may not have MS but also have problems of their own.

Andy: Dave, is your wife sensitive to temperature? I almost lose the ability to be a part of society once the temperature reaches 28°C

Dave: Thanks. Assuming that we can try to treat the depression, are there any practical treatments, similar I suppose to physiotherapy with muscular problems, that can help with some of the cognitive dysfunction?

Patrick - OT: Yes, plan what you need to communicate about and break up the conversation into short sentences with only one idea or concept in them. Give your wife time to compose replies and even write them down when they are said. Repeat answers back to her to reinforce what she has said and that you've understood. Try to limit the range of the conversation to the time that she can concentrate for then take a break and go on to the next bit. It sounds very artificial but can work well but if you've a backlog of talk, try to take it slowly and in order of importance.

Andy: Removing other stimuli such as sound helps me stay focused. I find it hard to live in the Playstation world of my nephews and nieces.

Dave: I am also interested in whether there is an established plan within the healthcare system for helping to either manage or treat these dysfunctions?

Patrick - OT: My worry is that even in healthcare there is poor understanding of cognition (thinking) and even less about how it can be managed often by comparatively simple strategies.

Dave: Any ideas whom we should turn to to help formulate these strategies and help put them into a simple format that others can pick up such as carers, friends, family, etc who interact with my wife?

Patrick - OT: A clinical psychologist or an occupational therapist with an interest in the area. I'd like to think any occupational therapist could come up at trial strategies in partnership with you, your wife, and family.

Andy: How much access and time to a neurologist does your wife get? Is she seen by an MS specialist neurologist or just a District General Hospital neurologist?

Dave: Very little, I keep getting pushed aside. Ideally I would like to try to get regular appointments over a long period of time to help formulate help similar to the support that a physiotherapist offers. Am I being too unrealistic to think that this is available?

Andy: One problem is the average UK general neurologist has is that they only see about 30 - 50 MS patients a year, and those patients are all at various stages of decay! My MS nurse has been useful in advising me on alternative neurologists that have different skills in different areas, does that make sense?

Jim: Can memory, like a muscle, increase with exercise?

Patrick - OT: We really don't know if thinking more helps like exercise does with muscle power. There have been some studies on 'normal' populations that say things like Brain Games don't improve thinking function but I am drawn to the idea that it can't hurt to do such exercises like crosswords, puzzles etc.

Andy: Patrick your comment about treating depression is interesting. How can we tell if we have clinical depression or are just fed up with MS?

One neurologist about ten years ago gave me Prozac, which I took for two weeks but it made me so jumpy and easy to spook. I got scared of my telephone ringing. Some folks say Prozac helps them cope but I found it quite the opposite!

Patrick - OT: Andy, you don't ask an easy question. Depression is much more common in people with MS than the general population but if I had MS I'd probably be depressed about it to some extent. That strikes me as normal. I think that if you've tried an anti-depressant and it didn't help then it is reasonable to not take it, what's the point? I think people can cope with being fed up but depression is really debilitating.

Andy: How can I tell if it's MS, a grumpy day, or debilitating depression? Are there other signs of depression which are not seen normally in MS?

Patrick - OT: Clinical depression is a pretty constant low mood with characteristics such as waking early with poor sleep, poor appetite and apathy. Mood might improve from morning to evening, with a general feeling of hopelessness and helplessness. Obviously it is a continuum. You need to talk to your GP about your mood and motivation.

Scoobs: Just wondering if there is any facility for a flash style chatroom to be made available on the MS Trust website all year round? Just a place for folk to pop in and have a chat?

Simon - MS Trust: There are no plans for a permanent chatroom from the MS Trust, though we will keep doing one day events a few times a year. For other groups, look at [Jooly's Joint](#), [MS People](#) or the [MS People UK discussion list](#). Alternatively, there are our [Facebook, Twitter, etc groups](#). That's just a smattering - there are plenty of others out there

Legs: Just wanted to say that once upon a time I had a photographic memory. But MS has put paid to that. To be fair I am the only one who notices and gets frustrated. That said I do have significant bouts of aphasia where I can not recall names (even my nearest and dearest) or common words. Sometimes with slurring of speech. This can cause embarrassment when at work. I am a professional senior manager in the public sector. The way I cope is that I think of ways around words. This means that I end up with a sentence as opposed to one word. The worst is that colleagues think I am being verbose. I have reduced my hours to three days as fatigue does exacerbate the problem.

Due to a lack of consideration I have been forced to leave permanent employment and have taken the route of interim management. Positive is that you can control the hours. Negative is that you only earn when you work. I found a significant lack of understanding and support with the Department of Work and Pensions (DWP) who can only seem to offer support if you are unskilled (via reemploy) or to keep you in work with the same inconsiderate employer. I would like to see more support through the DWP to help those with long term health conditions into employment rather than keep pushing people down the incapacity route as (a) they lose experience and skills (b) they pay.

Another tip I have used when undertaking a post graduate degree is that I learn information in three different sensory formats as opposed to one. So I use pictures, mind maps, audio, lists and even eating or sucking sweets.

Andy: I had the remembering names problem way before I was diagnosed with MS, its one of the reasons I could never have become a salesman. That and a bladder the size of a peanut LOL

Ellie: I too used to have a photographic memory, particularly for words and names. I still speak as rapidly, but then I just stop, and have no idea what the next word is supposed to be. It's the same when typing. Trouble is I am now 75, and not sure if it is MS or old age.

Jim: Many of the memory things people have said remind me of stuff in a book by Derren Brown (naturally I can't remember what it's called). He talks about assigning memories to points on a journey or places around a familiar room - making weird and bizarre pictures up to make the thing more memorable. He can remember a pack of cards at one viewing - I can sometimes find my house keys! It's all a question of degree.

Jay: Ellie, I'm 75 next month and also often wonder if my symptoms are age related or MS! I was diagnosed in 1975. Nice to hear from a contemporary.

Rowena: Ellie! It's not old age per se. I had a neurologist who said "we all have problems as we get older". I had the day before given a paper on semiotics to a very small group of people of seventy and eighty year-olds and they gave me a good and challenging run around!

Lynn - MS Trust: Thank you for sharing your experiences in the workplace Legs, I'm sorry to hear they were so negative. We really hope to increase awareness of the impact of cognitive difficulties in MS, especially at work. Please get touch if you'd be willing to share your experiences more widely.

Kim: I find I'm now hopeless at reading maps. I used to get about OK, but it's become a real struggle. Someone suggested that this might be something to do with my MS - could this be right?

Patrick - OT: It's not a complaint I've come across before but it is possible, perhaps having to shift between the real world and its representation on the map?

Kim: Yes. I'm better with road maps, but things like the Tube where it's a bit more abstract, I get quite flummoxed

Patrick - OT: People do underestimate the thinking that goes into translating from a flat map like the Tube one to which way to go and the platform. It may help to remember a sequence of station names on the route rather than the colour and east or west directions.

Jeanette: Hi Guys, I've had secondary progressive MS for about 15 years and I'm not taking any medication as I'm scared of the side effects. My balance is quite bad and I sleep in the afternoons. I don't work anymore as I'm too lethargic. My daughter has just had a baby and I said I would look after him for four hours a day whilst she goes back to work. He's six months old. Am I doing the right thing? I don't want to let her down after three weeks or so.

Kim: Jeanette, it's really up to you and how your energy levels are. Better to let your daughter know that you're seeing how you cope for a trial period perhaps. Or are there other ways that allow you to help out without running yourself into the ground?

David: I know we are all different, but I have the same diagnosis and the same problems, and there is no way that I could contemplate such a thing.

Patrick - OT: Jeanette, much will depend on the time, both when and for how long. I'd suggest that you try with a shorter period and not at the time you usually need a rest and see how it goes. Also having a 'phone a friend' back up plan might reduce your anxiety. Ultimately if it is too much you have to be honest with your daughter and perhaps find other ways to help?

Kim: David, you say you have similar problems - is this with looking after a grandchild? How have you found it?

David: I have similar medical problems and symptoms as Jeanette, but I know there is no way I could look after our two year old grandson. I often find that when he is around, that I have to go to bed for a lie down. I wouldn't want

Jeanette to find that this is the case, and that she has no other alternative. Just like everyone else, fatigue is a great problem, and would, along with cognitive issues make being able to look after a child very difficult and traumatic, and I wouldn't want to think of possible consequences should a problem arise.

Kim: I guess that's the advice ultimately, isn't it, David. Be aware of your limits and live as well as you can within them.

Julie2: A very interesting read - my problems are common and I'm not on my own. Any suggestions on how to make my legs feel less heavy? Taking just a few steps is such hard work

Patrick - OT: Is the heaviness constant or does it vary?

Julie2: Mostly during the day, but I notice when its time for bed late a night I feel stronger

Patrick - OT: It might help to keep a record for a few weeks to see how it varies and what affects you, if anything. It's boring to do but sometimes people find patterns to their fatigue that help with managing it.

Julie2: OK, I will try. I realise the less I do will make my legs weak, but it such a struggle and being strong minded as I am it very frustrating to be unable to lift my legs

Anita - psychologist: Hello. I am Anita Rose and I'm a clinical neuropsychologist working with people with MS.

Simon - MS Trust: Welcome to the room Anita

Lulu: As parents of grown up daughter we try to help with her 'business' affairs, eg buying a flat, finances, insurance etc. She is unable to do it herself, but we are told we are controlling and taking over her life. How can we overcome this perception if she is unable to do anything herself or think problems through because of cognitive difficulties?

Patrick - OT: I think this is common at some point or other to most parents. Maybe try to negotiate areas where you can step back and allow your daughter to make a mistake or two to see if this results in some learning? Who's told you you are too controlling?

Lulu: Our daughter tells us we are controlling. Her brain is damaged. We also help look after her small child on occasions and I know this is upsetting for her. She is profoundly depressed, feeling stupid and a failure. I know she is not but find it hard to find the words to give her the support, and empathy she needs

Patrick - OT: It is hard to get an accurate picture on these forums but it may be that she is transferring her own frustration at herself onto your attempts to support and help her. You might want to try a formal agreement or contract covering what you are allowed to control or interfere with, eg your grandchild's care, and areas where you agree not to be involved. You might want to consider

her having an advocate to help her get her point across without it becoming an argument?

Lulu: It's difficult because there are times when she is so grateful and then a bit later she is asking us to leave. It's the inconsistency I'm finding so hard to deal with.

Patrick - OT: Perhaps try shortening the visits or handover so once she's voiced her gratitude you leave before being tempted into other areas?

Anita - psychologist: It is very difficult when as parents you want the best for your children but the child sees you as controlling. This is something I see many times in clinic. Sometimes it is fear about the cognitive difficulties and the person is worried that others think they are stupid. One thing I encourage is for parents to sit down with their relative and negotiate areas where they can help and others where they will step back. I know this can be scary as she might make some mistakes but then sometimes it is important for us to make mistakes as that is how we learn. Have you been able to talk to someone about your fears for your daughter? Sometimes fear causes us to become over involved. I notice you say she feels stupid and a failure and you are not sure what to say - I would suggest just be mum! Sometimes you don't need to say anything - maybe give her a hug, buy her some flowers to say well done - for even a very small achievement. I am not sure if any of this helps?

Lulu: I've tried counselling, but unsuccessfully. Her present carer is brilliant, but will probably leave eventually, and our daughter and I feel that the financial matters are best dealt with by me.

Shortening the visits is a bit more of a problem because I live nearly 3 hours away and if I'm helping to look after her child for 24 hours then that's difficult.

Simon - MS Trust: Lulu, you may be interested to know that we will be running another chatroom on Thursday for partners of people with MS. Not quite your situation, but you may like to look in then too to see if people have experiences that may be helpful in your situation.

Lulu: Unfortunately I'm away on Thursday for the next chatroom, but will catch up with it when published.

Anita - psychologist: I am pleased she has a good carer and she obviously appreciates your support. It is a shame you will not be around for the carers' chatroom as I am sure you would gain lots of excellent advice and support - maybe you could speak to other carers via the MS Society's Discussion Boards?

Lulu: My daughter is desperate for psychiatric/psychological support but we are told there is no MS neurological specialist in her area. She has a good MS nurse who is very supportive but my daughter says she makes her cry every visit. What help can we find for her depression?

Anita - psychologist: If your daughter wants help she can ask her GP to refer to a psychologist in her local adult mental health team. Even if the psychologist doesn't know much about MS they will know how to help someone with depression and mood problems. I have psychologists from around the UK contacting me for support if they need it when working with people with MS. Also (I apologise for promoting my work!) there is a new MS Essentials Booklet available from the MS Society written by myself which is called Living with the effects of MS - in there are many strategies around depression. Maybe your

daughter might find that helpful. Also the MS Trust have some excellent literature as well.

Jeffrey: Your daughter is fortunate that you are a strong advocate on her behalf. Don't back off.

Lulu: Her GP says that with her brain damage there is not a lot a psychologist can do - but I simply can't accept that there is no one out there (not emotionally involved) who can't help either her or us to find strategies to deal with her cognition problems.

Anita - psychologist: All psychologists as part of their training learn now to deal with people who have cognitive problems. Now some like me do go on and become neuropsychologists others don't. My advice would be to either ask the GP to see if there is a brain injury/rehabilitation service with a psychologist - they might be able to help. Or you can contact your PCT (primary care trust) and ask them to help you find the psychology services in the area. Your local PALS (patient advice and liaison service) person in your local hospital might be able to help you find someone. Also you can look for a psychologist via the Find a Psychologist link at the British Psychological Society website.

I personally think some things can be done - but without assessment how much I cannot say. I believe everyone, regardless of cognitive problems, can receive some benefit

Patrick - OT: Although Headway is focused on people with acquired brain injury the local contact may be able to help you access local services under a different banner to MS

Anita - psychologist: Patrick's suggestion is a good one as well - guess what I was also trying to say was to look for support not under the banner of MS.

Lulu: Thanks Anita, Patrick and Jeffrey - will follow up your suggestions.

Jeffrey: Greeting everyone, it is a pleasure to join the discussion. I am Jeffrey Gingold, located in Milwaukee, Wisconsin, which is a bit north of Chicago, if that means anything to you.

Lynn - MS Trust: Welcome Jeffrey, great to have you with us

Jeffrey: I have had MS since 1996 and dealt with a list of physical symptoms, but I have a special interest in the cognitive aspects of the disease, so if anyone has questions...happy to chat.

Lynn - MS Trust: Jeffrey is also the author of two books on cognition and MS - [Facing the cognitive challenges of multiple sclerosis](#) and [Mental sharpening Stones: manage the cognitive challenges of multiple sclerosis](#) and is an advocate for people living with MS and experiencing cognitive problems in the US

Anita - psychologist: Jeffrey - pleased to meet you - I recommend your books frequently to my patients - they are excellent

Jeffrey: I have been flipping through the discussion that has occurred today, prior to my entry, and it is a pleasure to see that people are able to mention their cognitive concerns. Don't know about the UK, but here in the US, it has taken

some time for MS patients and some medical professionals to acknowledge and openly discuss cognitive impediments. Don't know how it has evolved in the UK, but treatment begins here with informed discussion. Excellent.

Beth: Jeffrey, have you had cognitive symptoms yourself, or is it more of a professional interest in this area?

Jeffrey: I have had cognitive difficulties, but they did not manifest themselves until several years after diagnosis.

Beth: Do you mind me asking how they affected you?

Jeffrey: The simple impediments are slowed recall and identification of previously known items, places and people. The information is still in there, but blocked and access is delayed. Multi-tasking is non-existent and it is very easy to be thrown off a discussion track.

Beth: Thanks Jeffrey - I find my own cognitive problems very frightening, so to hear from someone who is successful in a professional career and who experiences similar things to me is reassuring

Leonie: Hi Jeffrey - I have read your book and it was such a relief to see all the cognitive problems I had experienced described so comprehensively by a 'real' person with MS. It has inspired me to write something similar for people in the UK - and also from a female perspective. Modern woman are expected to be able to multi-task like never before and the realisation that you can no longer keep up with your peers is a double let down.

Jeffrey: I have learned to not take myself too seriously and avoid allowing MS cognitive moments to freak me out. With calm patience, the information has a much better chance to return. Also nice to have a safety person, one who already understands, is vital since the worst time to have to explain a cognitive jam is when you are in the middle of one. A safety person does not need an explanation when they see that blank look on your face.

When you are jammed by multi-taking, male or female, give yourself permission to take a moment and even ask others "for a moment" or to repeat/review the request. It gives your brain a chance to catch up and repetition is useful.

Patrick - OT: It's good to hear someone advocating the 'take a moment' strategy. I spend a lot of time teaching people to do that in their head so as to relax and let the recall happen.

Jeffrey: Patrick- I have felt that it is like a narrow funnel - jamming more into it does not clear it. Rather, slow the flow of information and it is much easier to resume the flow.

Patrick - OT: Oh, you can be certain I'll be using that metaphor now too!

Jan: What part of the brain is affected to cause cognition? And what does a T2 lesion mean?

Patrick - OT: We think about things in all sorts of different places and ways in our brain though some areas seem to do most of the work for some types of

thinking. A T2 lesion (to me) would mean at a particular level in the spinal cord Thoracic 2.

Simon - MS Trust: Although Patrick is right that T2 can refer to a particular vertebra in some contexts, when used in relation to MRI scans it refers to different types of scan. T1 scans are good at showing contrast between grey and white matter (different types of tissue in the central nervous system), whilst T2 shows up water content in tissue (as occurs within lesions).

Anita - psychologist: T2 is a type of MRI imaging technique in which TE and TR (Echo time and Repetition time) are longer and the image's contrast and brightness is determined specifically by T2 signals. In other words it is dependant on how quickly they look at your brain as to how lesions show up. A T2 Lesion will show up as white

You ask what part of your brain is affected to cause problems with cognition. Well it is important to say that each section of the brain has a specific central purpose or duty to perform.

The Right hemisphere controls the left side of the body is responsible for temporal (relating to the sequence of time or a particular time) and spatial (relating to space) relationships and is responsible for analysing non-verbal information and is also responsible for communicating emotions.

The Left hemisphere controls the right side of the body produces and understands language.

Now in MS sometimes where a lesion is will affect certain parts of cognition. But also because MS causes areas of demyelination throughout the Central Nervous System (CNS) and the optic nerves this affects the transmission of nerve impulses (messages) throughout the CNS. So a lesion might be in one part of the brain but the affect is seen in another part.

If you want more information the MS Trust has leaflets that describe this and the books by Jeffrey mentioned earlier are also very good

Simon - MS Trust: Jan, our basic guide to the symptoms of MS (to which Anita referred) is called [MS Explained](#)

Geoff: I found my problems with memory and concentration really hard to talk about. I could tell people that my bladder is shot and that sexual things are not good, but touching on the idea that my mind is going is usually too scary to contemplate. A room like this that allows people to discuss these problems is a great help

Beth: Yes, I think cognitive problems are the most scary - what do other people think? OK, there's not a 'good' symptoms, but wobbly walking I can cope with, wilful bladder is not fun, but things can be done, fatigue is a pig, but I can cope - but feeling that I can't think straight scares me.

Leonie: Anita, hi, it's Leonie from the CoSMos project. This chatroom has been excellent today. The transcripts will make great reading.

Anita - psychologist: Hi Leonie, good to see you here! I am in the process of writing a helpful cognitive tips guide/booklet - complete with removal/photocopiable pages so that nurses etc can really help people understand difficulties but also give them tips/templates etc to help. This I think is very important because as we know very few people are able to access neuropsychological support.

Jay: I saw a comment about arnica helping fatigue - would love to know more. Do you take it when you are fatigued or prophylactically to prevent it?

Jacqui: Hi I was diagnosed with primary progressive MS about two years ago. I am getting worse and have deteriorated more so over the last nine months. My balance is very bad and I've had some very nasty falls. I am like a parrot and keep repeating myself by asking the same questions just after I have asked it. Feels like my mind in a misty daydream in the morning and a fog by the end of the day. The usual busy bee (creepy crawly) feeling and a lot of spasms. God I could go on forever. I am lucky that I have a lot of help, but just wondered if anyone knew anything about the new drug LDN or any other wonder treatment for primary progressive MS?

Simon - MS Trust: No wonder treatments of primary progressive, I'm afraid. We did have chatroom on this last autumn. We also have a factsheet on LDN. Our Open Door newsletter has also had an article on homoeopathy, which makes mention of arnica.

Kate: In some circumstances cognitive problems can increase vulnerability to financial or other abuse. I haven't seen it mentioned here yet, and it is hard to deal with. It is mentioned in the NICE Guidelines on MS (Section 1.7.12 Cognitive losses)

Jeffrey: Cognitive problems can affect every aspect of daily life, but finances should be taken most seriously and if there are concerns, some trusted oversight is vital. It will also release some stress.

Anita - psychologist: Kate - capacity (ie the ability to deal with finances etc) is a very difficult issue to deal with. In my experience it is one NICE guideline that people find it easier to ignore!

Jeffrey: There is also a ego hit when you must ask for help, but once finances are messed up, there may be no going back to correct a mistake. Money disappears quickly and without apology. It should be taken as seriously as informed health care.

Kate: The problem I had was with carers when I was having a relapse that involved slow thinking and affected speech - it was not a good experience. Till then I had not thought of myself as a vulnerable adult and would have preferred to have had the information about the safeguarding adults team prior to encountering abuse. At least I would have had more confidence in dealing with the situation.

Patrick - OT: It's difficult to label oneself vulnerable, but you might want to investigate an independent advocate to make sure your point of view is heard within that context.

Anita - psychologist: I am sorry to hear about your experience. I totally agree with you information about safe guarding adults teams should be made more widely available. As an MS community I know we are trying to promote such knowledge and indeed I recently arranged a national study day for healthcare professionals about mental capacity and how to support people and about getting information out there. Thank you so much for highlighting this issue and hopefully people reading this transcript will be able to find their local team in case they might need it. Also hopefully it will also highlight to health professionals like myself the importance of highlighting such services and the need to support people with cognitive problems. I know things are changing as my referral rate for capacity assessments and input is rising weekly - but thanks again for raising such an important topic.

Billy: I cry when Liverpool get beat, and when they win, but why do I cry when a particular song is played or a comedy film is shown?

Jeffrey: I am sure that there is medical answer for what you are experiencing, but I refer to it as hyper-emotional moments. Some things just trigger my laughing or tears and I don't think it deserves that level of response, so I pause, chuckle at myself and move on.

Patrick - OT: It's the same process in each case but the filter you have to control the emotional reaction doesn't work quite so well so more things trigger the same reaction.

Anita - psychologist: Jeffrey's answer says it all. Yes it could be explained as he says with medical jargon but his suggestion of dealing with it is great

Billy: Thanks all, for your answers

Leonie: Jeffrey - would you say that your cognitive problems have bothered you less the more you understood what was happening inside your brain? I know my own anxiety levels were making things worse, but since reading up on things I am able to be more accepting that I can do most of the cognitive stuff I used to be able to do but just more slowly in and in shorter bursts. But the finances are a real challenge even with a calculator and a spreadsheet!

Jeffrey: The problems occur to my on a daily basis, but I know that it is a waste of time and my energy to fret about it. Through information and discussion, I know that I am not losing my mind - so why worry about it. Better to skip the invitations to any self-pity party, since I will mess up the addresses.

It is just like knowing how to get home, except one day the roads are ripped up and trees are down from a storm. That doesn't mean that I can't get there or life is over, rather, I must be patient [give myself a little more time] and go a different route - with the music in my car turned up even louder.

Regarding finances, it is important to allow time to review what you have done and not calculate when you are most stressed. Math is tough without MS, adding it doesn't make it easier, so review what you have done and acknowledge mistakes up front.

Natalie: One thing that I have noticed (and recently had confirmed by my MS Nurse) is that the MS is giving me PCA-, Alzheimer's- and aspergers-like symptoms, more and more as time passes.

Anita - psychologist: I am wondering what symptoms you mean?

Natalie: A whole list of symptoms. Sorry to be vague.

Beth: What is PCA?

Natalie: PCA is Posterial Cortical Atrophy - the variant of Alzheimer's that Terry Pratchett has - mainly based in the vision part of the brain.

Patrick - OT: The cognitive problems people with MS report are actually quite different to other dementias

Lynn - MS Trust: Jeffrey, a lot of the discussion earlier in the day related to the difficulties of managing cognitive problems in the workplace. I wondered if is there anything you'd like to share in this context.

Jeffrey: Beyond making your work space comfortable to not exacerbate MS symptoms, it can be useful to identify your best time to function and if possible, to slightly modify your hours to fit those hours and allow time for mental breaks - like recharging a battery. You wouldn't expect your laptop to function all day without a re-charge, so same for you too. Speaking to an appropriate HR manager is useful, so it is understood by management why some accommodation is good for you. Sometimes, better to identify the MS, rather than be written up for poor work performance

Anita - psychologist: I would agree with Jeffrey and also encourage people to talk to their MS OT and Occupational Health Advisors at work - they too will be able to help them adapt work.

Patrick - OT: We once arranged for a solicitor to have a programmed power nap after lunch. Otherwise it's usually been about making the working week more flexible so that the person doesn't work to such a level of fatigue that their entire life outside work is taken up with recovery. So day on/day off and half days have been very effective. Also had someone who attended big meetings get the typed minutes the same day so they knew they could review them in a quiet office.

One thing that seems to be key is taking the time to educate the direct line manager as they will have lots of lay attitudes and assumptions about someone with MS and they are often really, really wrong through ignorance.

One example I use to get MS fatigue across to someone is get them to think about when they first had their children and had had no real sleep for weeks and how that felt and then say "that's getting sort of close to MS fatigue"

Billy: Educating the line manager is only good if the rest of management staff and other colleagues are equally educated.

Patrick - OT: Yes Billy you are right, but you've got to start somewhere though.

Simon - MS Trust: With employment issues, there will be useful information in our previous chatroom on that topic and also in the book *At Work With MS* (both available through the MS Trust website)

Simon - MS Trust: I think we're pretty much up to 7pm now. Thank you to Patrick, Jeffrey, Anita, Dawn and Terri for their contributions, and to all the people who have shared their comments and questions today

Resources mentioned in the chatroom

Other than our own publications, the MS Trust can not vouch for the content of the information listed

MS Trust

StayingSmart - www.stayingsmart.org.uk

a web-based resource designed by the MS Trust for people who want to know, or know more, about how MS can affect thinking

Books

- At work with MS
- Living with fatigue
- MS explained

Factsheets

- Cognition
- Diet
- FES (functional electrical stimulation)
- LDN (low dose naltrexone)

Chatroom transcripts

- Employment
- Progressive MS

Website resources

- Living with MS - driving and transport - www.mstrust.org.uk/information/livingwithms/driving.jsp
- Map of MS services - www.mstrust.org.uk/information/services/

Open Door articles

- Managing stress in multiple sclerosis - February 2009, pp12-13
- Losing concentration - May 2009, pp12-13
- Homoeopathy and multiple sclerosis - August 2001, pp4-5

Open Door is the MS Trust's free, quarterly newsletter

All of these publications are free

To order MS Trust publications or to join the Open Door mailing list:

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info@mstrust.org.uk

Contact the MS Trust Information Service

01462 476700

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Other resources

Online MS groups

- Jooly's Joint - www.mswebpals.org
- MS People - www.ms-people.com
- MS People UK discussion list - <http://tinyurl.com/mspeopleuk>
- MS Trust Facebook and Twitter groups - <http://tinyurl.com/rygls3>
- MS Society's Discussion Boards - www.mssociety.org.uk/a_chance_to_talk/

Books and publications

- Susan Allport.
The queen of fats: why omega-3s were removed from the western diet and what we can do to replace them.
University of California Press; 2008
- Derren Brown.
Tricks of the mind.
London:Transworld;2006
- Jeffrey Gingold.
Facing the cognitive challenges of multiple sclerosis.
New York:Demos Medical Publishing;2006.
- Jeffrey Gingold.
Mental sharpening stones: manage the cognitive challenges of multiple sclerosis.
New York:Demos Medical Publishing;2008.
- MS Society.
MS Essentials 28: Living with the effects of MS.
London: MS Society; 2009
- NICE.
Multiple sclerosis - understanding NICE guidance.
London: National Institute For Health And Clinical Excellence;2003.

Other resources

- British Psychological Society -
0116 254 9568 / enquiries@bps.org.uk / www.bps.org.uk
- Headway - the brain injury association
0808 800 2244 / www.headway.org.uk
- University of Southampton cognitive behavioural therapy trial (MSInvigor8) -
<http://tinyurl.com/MSInvigor8>
- EYE Q - a supplement containing Omega-3 and Omega-6 oils. Available from high street chemists