



Cognition and MS

Chatroom

22 November 2011

www.mstrust.org.uk

MS Trust, Spirella Building, Bridge Road, Letchworth Garden City, SG6 4ET
Reg Charity no 1088353

Cognition and MS

22 November 2011 - 10am to 7pm

- **Fiona Barnes** - MS Nurse
- **Joan Regan** - MS Nurse
- **Jo Johnson** - Neuropsychologist
- **Patrick Carroll** - Occupational Therapist
- **Jeffrey Gingold** - Advocate and author
- **Dawn Langdon** - Neuropsychologist

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

For further information on topics raised, please contact the
MS Trust Information Service on
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Simon - MS Trust:

Welcome to today's chatroom on cognition - memory, concentration and the effect of MS on thinking

Anne:

I have had a few 'brain freezes' lately. For instance, I plugged in the Hoover and then couldn't turn it on, I didn't know how. They don't last long but it's a thing I do all the time without thinking. Is this the MS?

Geoff:

I get that too. I find myself completely befuddled and not knowing what to do next

Fiona - MS nurse:

Anne, it may be helpful to break the task down into small chunks. Think the task through as step, 1 plug Hoover in, 2 switch on, etc. The other thing is to reduce any distractions for example turn off the radio, focus only on the task.

Geoff:

This is very true. I find if I sit down and try to clear my mind for a few minutes, then do one thing at once, I'm OK again

Fiona - MS nurse:

Thank you Geoff, it is good to hear that concentrating on one task at a time helps you achieve it

Geoff:

It took a while to work this out, and is a pain to my family, but knowing how to find my way round it to some extent has been a relief for me

Jo - neuropsychologist:

MS does produce thinking changes and so this could be an example of this but it could also be just a normal slip of attention that any busy adult might experience when we have too much on our minds. Have you had a look at the StayingSmart website?

Simon - MS Trust:

StayingSmart is a website about issues to do with thinking and MS and can be found at www.StayingSmart.org.uk

Jo - neuropsychologist:

Doing lots of things at once is often hard when you have MS and also being easily distracted is very common. I agree with Fiona, it is important to try and focus on one thing at a time and reduce distractions. Writing a plan for each day and a list of things to do can help you focus and achieve as much as possible

Changes in thinking do often impact family as much as the person with MS and sometimes they need to have time to work out how to help and get used to the changes. StayingSmart also has a section for family and gives strategies that will help everyone cope better.

Anne:

I am usually very good at organising around the MS and, as much as it is very frustrating, I think I cope with it as best I can. But this complete 'brain stop' frightens me and all I can do is wait till it starts again and carry on with whatever it is I am doing. Maybe the fatigue affects it?

Jo - neuropsychologist:

Fatigue will impact thinking but also anxiety will make it worse, so reassure yourself it is part of the MS, you are not dementing or going mad. Often these problems stay stable, so try not to panic.

Fiona - MS nurse:

Yes, if fatigue is a problem for you it could also be contributing to the 'brain stop' you describe. Try to manage the fatigue by not taking on too many tasks, pacing yourself and resting regularly. You say that you feel frightened. This can make the problem worse. Reassure yourself that if you rest, your brain will 'unfreeze'

Anne:

Thank you for your reassurance. I think it frightens me because I have no control at all over it, whereas other symptoms I can manage, in a way.

Jill:

Yes, Anne, I know what you mean

Jo - neuropsychologist:

It is frightening because it is invisible and other people don't understand thinking changes BUT it is manageable in the same way as physical challenges. You need to find out what the specific problem is. StayingSmart and your MS nurse can help and then you can then find a strategy. For example, if you can't remember a name, think to yourself that others won't notice or just say, 'remind me of your name'. Once you feel confident you can manage each cognitive issue, you will feel better about it and that will help too.

Jill:

I find I'm struggling at work. Physically I'm OK, but I find the thinking side of the job more of a struggle as the day goes on - harder to concentrate, losing my place and so on. Any tips?

Joan - MS nurse:

Sounds like fatigue may be a problem which could reduce your concentration. Have you tried taking regular breaks? Other things to consider would be to make sure you drink plenty of fluids and have meals breaks during the day so that your brain has fuel to work on. Also concentrate on one task at a time for example either answering the phone or reading your emails

Jo - neuropsychologist:

Are you able to take plenty of short breaks? Even if it is just five minutes for some fresh air, that will help. Keep hydrated and eating regularly will all help with fatigue.

Processing things quickly and getting distracted are common problems so, as I said earlier, find as quiet a space as possible and plan each day in a very clear way. Ticking off tasks as you go really helps with the organisation. Both the MS Society and MS Trust can give advice about how to get help at work.

Jill:

It is difficult in an office where we're always on the go - but on really busy days I'm useless by 3 o'clock

Jo - neuropsychologist:

Can you speak to your manager? You are entitled to support under the Equality Act. Could your MS nurse support you in talking to your employers about what you need?

Jill:

It has been tricky - but as much because of me as anyone at work. When I was diagnosed I think I came to terms with the stick or wheelchair thing - the things you hear about but which I don't need yet. But finding my thinking was scrambled is very, very scary and I think I'm still trying to deny it to myself to some extent

Jo - neuropsychologist:

What is your job? Denial can be helpful and we all manage certain problems in that way. However sometimes if you keep denying then you can't get the help you need and the problems defeat you more than they need to!

What frightens you? Understand that it is not a dementia and that you are no less intelligent but MS produces certain specific changes to the thinking as it does the body. Lots of people fear these changes the most but acknowledging them and talking to people can help.

Jill:

The people I've talked to have been supportive, but maybe I'm my own worst enemy - a bit of a control freak and getting frustrated with myself (while still recognising that this makes things worse)

Jo - neuropsychologist:

Jill, don't beat yourself up. We all like to be in control and it is hard when MS challenges your sense of self. Have you seen the book *Shrinking The Monster*, which is available from the MS Society? Lots of people felt that way of thinking helped with regaining a sense of control.

Simon - MS Trust:

You can find Jo's book *Shrinking the Monster* on the MS Society website. Jo also wrote about this in an article in the August 2008 issue of Open Door (see the Resources section at the end of the transcript)

George:

I am a senior citizen with MS for more 25 years. I've noticed that my memory has got worse. I can't often remember short-term things but have no problems remembering what happened more than 65 years ago. Is this just something all us old people experience or is MS playing a role here?

Jo - neuropsychologist:

George, you raise an interesting issue. It is common as we age that long-term memory stays fine but short-term memory gets worse, so the changes you are noticing may well be normal aging. Compare yourself with your friends the same age. However, MS also impacts short-term memory and especially concentration. If you are not concentrating or not interested (a man thing!) when you are told things you won't remember them.

Suzy:

I forget words - often mid sentence! I now realise how horrible it must be for someone with a stutter when people finish off words for them. I find the only way to cope is to turn it into a joke - try and describe what I'm trying to say and letting people guess. But it does make me feel stupid when I'm with people I don't know.

Joan - MS nurse:

I think that is a great way of dealing with this problem. Have you thought about telling people when you meet them that this can be a problem for you so that they understand?

Jo - neuropsychologist:

This is very common and you are doing the right thing by finding ways around it. StayingSmart has some other strategies too, to manage this problem. I am sure people don't notice and actually it is a change that often occurs during the menopause so there are probably lots of other women in their 40s and 50s also feeling self conscious. We focus on ourselves and think it is obvious to others but often people are far too preoccupied with what they are saying. Try and remember the last time you noticed someone make an error in speech. Feeling stupid will make it worse

Suzy:

Jo, I didn't know that! I was assuming it was MS or senility... Without being too flippant, I really don't want to let on to husband and son that my hormones could be to blame. They already roll their eyes at me and laugh at hot flushes :-)

Jo - neuropsychologist:

It is probably a combination of hormones and MS but I think if you talk to other menopausal women you will find they are struggling with words too and I bet you have not noticed!

Kate:

I have some undiagnosed language problems - called lazy or stupid at school 50 years ago and dyslexic type at university in my 30s. I'm now having quite a few cognitive problems which I call 'slow thinking'. I manage them well using the things mentioned already - resting and eating regularly and understanding as much as I can about it. It seems to me that I developed good strategies to deal with the language problems before MS, but MS is breaking the strategies down. This is causing problems communicating with others and I'm finding it difficult to explain what I think is happening, which is causing frustration and anger and changes in behaviour.

To me it is important that the pre MS language problem is recognised for what it is and that it is interacting with MS. Sometimes my thinking and communications are fine other times they breakdown badly.

I recently saw a neuropsychologist whose comment was that I could string sentences together okay and there wasn't a problem. Any comments or advice please?

Jo - neuropsychologist:

It is hard when you know you have a problem and someone tells you you are fine. Sometimes the problem is that the tests we use do not pick up subtle or higher level language problems. It may well be helpful to request a referral to a neuro speech and language therapist to try and tease out the problems and to advise.

George:

Kate, your written words look fine to me. When you experience problems, is it when you have to speak and you feel nervous? If this is the case, suggest you breathe deeply and try to be relaxed before you speak.

Kate:

Hi George. The problem is with both the written and spoken word. With writing I have time to correct things (if I spot them) - so I prefer using a computer and emails. I have a community matron and most of my communications with her are by email. With speech there are, and have been since childhood, problems with using the right word, word order, spelling, verb tense etc. When this happens with carers and others I have to rely on, it can cause all sorts of misunderstandings. I seem to be losing the ability to deal with the misunderstandings. I agree with you about breathing and relaxing

Jo - neuropsychologist:

Kate, I wonder if what you are struggling with is your longstanding language problems but also other related MS thinking changes. Processing information accurately and reading the emotions of others is now known to be a problem for people with MS so maybe these problems are also impacting your relationships and causing misunderstandings?

Kate:

Thanks I hadn't heard of neuro speech and language therapists. I feel that as I have secondary progressive MS and have had the language problems for so long - and from before I had MS - I had learnt how to deal with them there isn't anything that can be done about either. What I want is for the problems to be written down clearly with advice on how carers and I work together when things are bad with me. The only strategy I'm developing at present is asking them to leave me alone till things have settled, as being asked questions makes matters worse.

Jo - neuropsychologist:

Perhaps you need someone outside of your system, like an MS nurse or an advocate. They can have a look at the nature of the problems and then help educate your carers about the nature of the problems and how to help. Asking for some space sounds like a very positive strategy.

Kate:

Oh yes I've got plenty of the MS problems as well. I seem to distinguish when it is the language stuff as well. I think that is because my feelings now when it is both that resonate with how I felt with teachers.

Kate:

Could you tell me about assessments under the Mental Capacity Act? This has been mentioned a couple of times, and I have resisted as I thought it was to do with mental health. But recently I heard it also covers communication problems and that doctors etc should communicate with me in a manner that is appropriate for my disabilities. I was also told that the assessment was patient centred so would have to include the non-MS things and how they all interact.

Jo - neuropsychologist:

The Mental Capacity Act is there to protect people. It may be that people feel you need more support. The Act can only look at one issue at a time, for example, does someone have capacity to keep themselves safe or manage their money. It then looks at whether you can understand all the issues and tell others clearly what you want. The Act always has to be used in the patient's best interests. There are some good booklets around explaining the act very clearly. If you have a social worker I am sure she/he would be able to get you information. If not, your GP might help.

Kate:

Do you know if there are any patient centred booklets available? I've only seen things written for professionals. I can understand the issues about decisions I need to be making, which include my living arrangements, but the communication problems are causing me huge problems in getting things to happen. Who does a Mental Capacity Act assessment?

Jo - neuropsychologist:

Any professional who knows you well can do a Mental Capacity Act assessment. The Ministry of Justice produces information on the Act (see the Resources section at the end of the transcript).

Bill:

Does depression affect concentration and finding the correct word? I do get bouts of being very down and my mind almost seems to close down

Fiona - MS nurse:

Yes, depression can effect your concentration and word finding. Have you had any help or treatment for your depression?

Bill:

It can be hard work. When you're down you don't do anything. When you're not down, you don't think you need anything

Jo - neuropsychologist:

Bill, low mood will certainly impact your thinking and motivation. The challenging thing is that MS causes depression, fatigue and concentration and they all then impact each other. CBT or cognitive behavioural therapy is very good for people with depression. I have found *The stress and mood management program for people with MS* by David Mohr really helpful for mild depression. Have you spoken to your GP or MS nurse about your mood?

Simon - MS Trust:

Details of the book by David Mohr are listed in the Resources section at the end of the transcript

Fiona - MS nurse:

Bill, it can be hard work. When you do feel down, it would be helpful to discuss how you feel with your MS nurse and/or your GP as there may be treatments to help your mood and feelings.

Helen:

A lot of my time is spent with my mum, who is 58, and my Grandma and Grandad, who are in their 80s. I find that I have very similar thinking problems to all of them - forgetting the names for things and having to describe them, not remembering what I am doing part way through or how to do very simple things. I describe it as 'my brain is not working'. It doesn't scare me at the time as I know it will start working again soon but it can be a bit frustrating. What worries me is the fact that I am only 29 and find it easier to relate and communicate with people who naturally have thinking issues due to their age. I find it very difficult relating to people my own age who always seem to have so much energy and think very differently from me. It actually makes me feel very lonely and I worry what will happen when the people I can communicate with are no longer here.

My main symptoms are fatigue and generalised pain, so it has been very difficult to get a diagnosis as I always perform well during neurological tests. I agree, being told that there is nothing wrong with you when you know there is can be very frustrating.

Jo - neuropsychologist:

How tough for you. I think older people often have more understanding than younger ones about mental and physical changes. However, it is important to try and seek opportunities to meet with younger people too. Perhaps you could try more structured activities like an evening class, or church groups can sometimes be more accepting of people with additional challenges. The research shows that social contacts help people to cope better. Perhaps ask your family to help you brainstorm any activities that might suit you.

Cheryl:

I'm an artist. I don't know whether it's just the way I work, but I can't seem to concentrate on one bit of the picture for longer than ten seconds at a time.

Joan - MS nurse:

Hi Cheryl, that must be so frustrating for you. Are you having regular breaks, ensuring the room is well ventilated with good lighting? Also ensure there are no other distractions.

Jo - neuropsychologist:

Concentration is probably the most common problem in MS. Try and do all the things suggested earlier about reducing distractions, drink water, eat regularly and take breaks.

Emma:

My guess is that getting to see a psychologist might be difficult. What sort of support is available from my MS nurse? My thinking is similar to the person earlier who talked about getting fuzzier in the afternoon and forgetting words

Jo - neuropsychologist:

Emma, sadly, neuropsychology is not always easy to find. Your MS nurse will know what is available near you and how long the wait. Also, the MS Trust map (www.mstrust.org.uk/map) shows where psychologists are. Your MS nurse will be familiar with all the problems MS causes including thinking and mental health challenges. Fatigue management might also help if the afternoons are worse.

Simon - MS Trust:

The MS Trust book *Living With Fatigue* may be helpful with this.

Phil:

Is MS like Alzheimer's? My sister can get very forgetful and mixed up and I'm scared that is going to end up like my Gran

Jo - neuropsychologist:

Phil, absolutely not! MS does produce changes to thinking, but this is very different to dementia. The most common problems are thinking more slowly, being easily distracted, short-term memory problems and difficulties with planning and organising. People can often use strategies to help and it often stays stable for many years. The MS Trust and MS Society both have good information leaflets on these problems and how to help. There is also the StayingSmart website, which will help you understand the problems and help your sister.

Fiona - MS nurse:

Phil, no, the memory problems that people with MS have are different to those of people with Alzheimer's. Memory problems in MS can often be managed and are made worse by factors such as fatigue, poor sleep and low mood.

Phil:

Thanks, I'd been scared to ask the question before. I'll have a look for things you say

Simon - MS Trust:

Phil, the MS Trust has a factsheet on cognition and we've run chatrooms on this before. We also have the StayingSmart website. There's also info on cognition on the MS Society website. See the Resources section at the end of the transcript.

Jeff:

Someone mentioned CBT earlier. I know the phrase but don't really know what it means. How can that help?

Fiona - MS nurse:

CBT is cognitive behavioural therapy. It is often used to help manage depression. It involves altering negative patterns of behaviour and thinking into more positive patterns. That is, it helps people find their own coping skills to deal with their low mood.

Jeff:

Thanks. How is this done? Is it something you do at home, or do you have to see someone (nurse? therapist)?

Fiona - MS nurse:

CBT is done with a trained cognitive behaviour therapist, referral to whom can sometimes be made through your GP if he or she thinks it could be helpful. It involves doing some 'homework' between sessions. There is a self help website which uses a CBT approach at www.livinglifetothefull.com

Jeff:

Thanks, Fiona

Diane:

I have problems with finding the right words and often call people by the wrong names, which I know I've done as soon as I say it. My short-term memory is really bad. I don't think it's concentration as I score very highly on the number test they do for MS. I also find it difficult talking to a group of people, even friends. I get quite tongue tied and can feel myself getting stressed. I'm 63 and do wonder if it's the start of Alzheimer's

Joan - MS nurse:

Diane, word finding difficulties are very common in people with MS. You might find it helpful to let people know you have this hidden symptom. Try and plan ahead what you wish to say. If you can't find the right word then try describing it or use gestures. Getting the message across is what is important.

Tricia:

I often have problems with finding the right words but mainly when I'm tired so I do put it down to fatigue. Although sometimes I can put a very odd word in a sentence this amuses my other half greatly! I do share others concerns about how MS can affect your thinking. It seems very scary as quick thinking and good memory is very much part of what I am and what I do.

Frances:

Are there drugs that help with memory and concentration? Or am I just fantasising about a quick fix?

Joan - MS nurse:

Frances, There are no drugs that are specifically prescribed for the treatment of memory and concentration. There are strategies which you may find helpful which are not quick fixes but can be very effective. The StayingSmart website is also very useful

Trudi:

My problems get worse when I'm too hot, too fatigued or, perhaps surprisingly, when I'm talking to more than one person at a time - the more people, the more befuddlement. I just can't think of/get words out. My sentences grind to a halt and hang while I think. Any tips?

Frances:

Trudi, I get that too

Simon - MS Trust:

Trudi, not specifically about thinking, but the MS Trust book *Living With Fatigue* has lots of help for dealing with that symptom. We also had an article on staying cool in our Open Door newsletter (details in the Resources section at the end of this transcript)

Fiona - MS nurse:

These are common problems. It would be useful to try to keep cool and manage your fatigue. When you are talking to more than one person, face the people you are talking to and try to avoid distractions (do not look at things going on around you). Take your time when talking and if you cannot find the right words try talking around the subject

Sheelagh:

Can some of the drugs taken for MS also have an effect on memory and thinking or it is mainly caused by the MS? My husband not only forgets words or to do things on a daily basis but he also does silly things like putting the dirty cup in the fridge instead of the dishwasher and when I ask him he just says 'sorry I forgot'.

Joan - MS nurse:

Some of the medications used to manage symptoms such as pain, spasticity, sleep problems and low mood can also affect memory and thinking. It may be an idea to discuss medications that have this effect with your MS nurse or GP.

Liz:

Is this down to specific medications, or can it sometimes be the combination of several - eg taking different things for different symptoms

Sheelagh:

He takes several medications including Lyrica (pregabalin), Laroxyl (amitriptyline), Cymbalta (duloxetine) and sleeping pills and says he doesn't like the feeling of being not in control of his thinking. I guess it could be a combination, what do you think? Are there any of them that are more likely to disrupt memory than others?

Liz:

I found I was more muddled headed than usual when I was taking things for spasticity, pain and also high blood pressure. Could be coincidence

Joan - MS nurse:

The benefits of these medications need to be considered along with the possible side effects. A discussion with the GP/neurologist will identify if any adjustments need to be made.

Sheelagh:

Joan, I agree that the side effects should always be considered however in reality it is not always the case. I think the pain or depression is the priority not the side effects when the prescription is being written.

Sheelagh:

Is there a way of knowing if some medications cause more cognitive problems than others?

Patrick - OT:

I think you can only 'try' them when the doctor prescribes a medication and see if you notice any changes.

Vicky:

I am sat laughing to myself reading some of these posts because honestly I also do a lot of these things especially same as your husband, Sheelagh. I put strange things in the fridge and try and unlock the front door with my car keys by pressing the open button - so it is reassuring to know I'm not on my own

Anna:

Vicky, laughing at myself has been a good defence. At first I tried to hide my lapses and felt horribly guilty and on edge all the time. I find if I laugh first, it gives me some control of the situation, if not necessarily my thinking

Vicky:

Thanks Anne. I think some days if I can't laugh at myself I would just sit and cry - and that would get me nowhere

Sheelagh:

Vicky, you have made me laugh thank you. My husband hasn't tried to open the front door with the car keys as yet - mind you he can't normally remember where he has put the keys in the first place.

Vicky:

I am forever searching the house for the car keys

Liz:

I find I have to always keep things like keys in the same place or I will never find them. Remembering to put them in that place is another challenge. The family are good at tidying up after me

Fiona - MS nurse:

Being organised and having a place for everything is a really useful strategy to help manage losing things due memory problems. Can your family help in keeping your things in their set places? Some people use a key ring which has an alarm (see StayingSmart website)

Vicky:

My children are only young but on a morning have realised that I will spend 20 minutes looking for the keys, so if they want to get to school on time they have to help me - it's like a game for them

Patrick - OT:

Practically, if you can make one place to keep keys then you are likely to learn it over time. You have to develop a habit that the keys go there or in your hand to start the car and those are the only two places the keys are allowed to be. It'll take a bit of time to establish the habit but one of my clients found this strategy really effective.

Vicky:

Thanks for that Patrick, I will try my best to do that but half of the time I have put the keys somewhere without realising. It's just a bad habit I have I think

Rachel:

I often find myself thinking backwards - I'm walking to the car and look at the hand the keys should be in, and then work my way back in stages to the hook where we hang them.

Patrick - OT:

Rachel - "hook where we hang them". An excellent example of the benefits of having a consistent place where keys get put.

Rini:

Hi. The only way I can help is to say I've had to become super organised. If I was not, life would be a total disaster. Keys in the drawer at the front door - ALWAYS. If someone moves something or puts it in the wrong place in the kitchen, it's a panic. I know easier said than done. It's taken 20 years to arrange things so it's easier for me.

Vicky:

I am definitely going to practise putting them in one place so it gets drilled into me. Thanks

Patrick - OT:

Make sure everyone knows the place and if they see the keys they are picked up and put there. We had one person whose children would chant "keys on the hook" every time they came home!

Vicky:

I think that's a brilliant idea it's nearly time to pick them up from school so when we get home I will show them where we going to keep them and ask if they see them anywhere else to make sure they are put where they should be

Patrick - OT:

It's always better to get the rest of the family involved, the person I mentioned now has two teenage children who still say "Keys on the hook" even when they come home on their own, it's become a family tradition instead of "I'm home"!

Sheelagh:

Thanks Patrick. Unfortunately my husband feels off the planet most of the time, the mixing up of the dishwasher and fridge is just one silly example. There are numerous others not all funny. In general he does not feel in control of his mind. I think it's a chicken and egg situation - the medication controls the pain and helps depression but in return the side effects are equally as difficult to live with.

Patrick - OT:

I'm thinking through the dishwasher/fridge thing. Initially you could try a clear label on the door of each, use Blu-Tack as they can come off if people are visiting. That may be enough to trigger the right association for your husband to put the cup in the right machine?

Rachel:

I find I cry at the least thing or sometimes find myself laughing at nothing. Not necessarily anything sad or funny, but I can't control my response. Is that MS?

Joan - MS nurse:

Yes this can be a symptom of MS which affects a small number of people where you are emotionally very sensitive. Have you mentioned it to your neurologist? A neuro-psychological assessment will help to identify ways of managing it. It is also a good idea to let friends and family know that you are experiencing these feelings.

Rachel:

Is there anything that can be done to help?

Joan - MS nurse:

The assessment will help in identifying exactly what is going on and from that a treatment plan would be made.

Maria:

Wish I could join in, but concentrating on reading and it all sinking in is beyond my brain today :(

Patrick - OT:

Maria - you can read the discussion afterwards and in short "chunks"

Simon - MS Trust:

The transcript of today's session will be posted on the MS Trust website. If you'd like a reminder about this (and about future chatroom events), send an email to the MS Trust at info@mstrust.org.uk

Maria:

Thank you Simon and Patrick

Bryan:

A few years ago there was a lot of publicity about brain training games and the like that could help mental ability. Is there anything in this, and if so, would it help with MS?

Patrick - OT:

Strictly speaking there isn't any evidence that they have a long-term effect. But I think it's like any skill, if you practice something you get more confident and better and if that helps you then that's the benefit.

Bryan:

Is there anything of that sort for MS issues in general, or is it a case of being regular in the specifics of your life - things always in the same place, doing things in the same order to remember all the steps, etc?

Patrick - OT:

Bryan - it is very individual, some strategies work really well for one person but not the next. Most of the time I try a series of strategies, trying to keep them simple and straightforward and take individual things one at a time. So as you mentioned, if maintaining concentration is difficult, treat the task on its own and do it in a place with minimal distractions. If you worry about all the other things that need doing put them in a list and work down the list.

Bryan:

My life is lists (always keep the notebook in the same pocket)

Patrick - OT:

Simple is best. Most of the new mobile phones have good diary and alarm/reminder systems as well. I use a notes app myself.

Bryan:

Good idea, hadn't thought of that. Thanks

Patrick - OT:

Provided you can learn the foibles of a mobile phone, they can be very useful. You can put things in way ahead with reminders so you never get caught out by not turning the calendar over. Many have a recording function that acts like a Dictaphone - another quick way of making a note, though you have to remember to play it back!

Nigel:

I agree with an earlier posting about concentrating on one item/task at a time. Flitting between things, no matter how trivial they might be tends to lead to stress and mental overload and the result is nothing is achieved. Does anybody find problems reading paper based information?

I haven't read a book for years as by the end of a chapter I have forgotten the beginning. The same applies to letters no matter what the content is. The same information on a computer screen is a different matter all together. I can assimilate the information. People who don't e-mail me cannot expect a reply. I can't understand the letter so treat this as an element of my disability.

By the way, that isn't an advert for Kindle!! I despise them.

Patrick - OT:

That's quite interesting, have you tried reading a book on the computer display? A Kindle is a different display. They went to great lengths to replicate the 'ink on the page' experience.

Nigel:

Does anybody have problems with these small data boxes? With only a small area to view ones pearl's of wisdom, I can't recall what I have typed from the previous sentence.

Simon - MS Trust:

If you use a Firefox or Safari browser you are able to resize the Comments window so you can see more of what you are typing. Just the little lined triangle in the bottom right corner. Internet Explorer doesn't do this. Only have these three browsers to hand so don't know what Chrome or others do.

Patrick - OT:

The joy of Safari - just resized my window

Shirley:

Have just discovered the StayingSmart website thanks to finding this chat, so I'm pleased to find out a lot of things as I am having problems at work at the moment

Patrick - OT:

Shirley, is there anything specific you'd like to ask about work?

Shirley:

Trying to maintain consistent performance as they are getting rid of people on performance and sickness. It's hard trying to explain the problems I have to them in a way that doesn't sound like I can't do the job.

Patrick - OT:

Is it a big company? No names but is it larger than 15 employees and are they aware of your diagnosis?

Shirley:

Yes it is and yes they do

Patrick - OT:

Are they amenable to having a discussion about adapted work? The MS Trust have a self assessment form for work that could be useful for structuring what you need adapted without making it look like you can't do the job.

Simon - MS Trust:

Shirley, the form that Patrick mentions can be found in the Work toolkit on the MS Trust website. We also have a book called *At work with MS*, the second edition of which has just been published.

Shirley:

Thanks. I will look at the self assessment form. My discussions with them have not been the best.

Jeffrey Gingold:

Greetings everyone, it is still morning here in the US and I am onto the third cup of coffee. I have read the conversation and I am impressed about the honest sharing that I see... it is a great way share and learn from the successful experiences of others. Please carry on.

Sharon:

I find that when I am watching television, if asked what just happened or what was just said, I haven't got a clue. But it all pops up in my mind about 20 minutes later. My hubby thinks I just don't want to answer him, but I honestly can't remember what was just said!

Patrick - OT:

Sharon - is it only when you're watching television that you get this delay?

Sharon:

No, I have this all the time. If I get lost when I'm driving I'll turn down a side road do a three point turn and have no idea whether I just came from the left or right if the main road.

Patrick - OT:

How does it come back? You mentioned that later you can remember what was on the TV. Driving, I suppose a satnav would help, provided you've programmed your journey in. Have you spoken to the GP about this and asked for a memory assessment?

Sharon:

The answer to the question I was asked about the TV will just pop into my head 20 minutes later from nowhere - and by that time no one wants to know the answer! The invention of Sky+ has helped with the rewind button!

On the driving front, I got fed up of being afraid to get lost and have stopped driving. I had a memory assessment which highlighted that I have delayed recall and that it is consistent with my MS and was offered no remedies. Is there something I could do to help?

Jeffrey Gingold:

Sharon, I frequently become confounded when driving and often forget why I got into the car. Again, I rely upon a list of tasks and know that I can re-refresh my purpose with a glance at the list. Without it, I am at risk of needing to pull over and figure out where I am going. You are not alone.

Patrick - OT:

Sharon - unfortunately the only remedy is to adapt to the change in your memory, I haven't come across delayed recall but can see that the facility to rewind the TV can help. Digital radios can do the same thing. Does the media make a difference, is it easier to recall visual things or verbal information?

Jeffrey Gingold:

The good news is that you are not losing your mind. I was informed that the information that I could take for granted, knowing faces, locations and directions, had a hitch... a delay of access to the information, but the details have not been erased, just perhaps delayed. Still frustrating, yes.

Sharon:

Patrick, it doesn't make a difference in the media type whether visual or other! I have great fun on the phone with my niece who also has MS. If we are interrupted momentarily neither of us can remember what we were talking about just seconds ago. I used to be a PA and could tell you that the info you are looking for is ten pages back on the left hand side fifth line down. I guess it's just a bit frustrating that I no longer have the memory I once had!

Nigel:

Anybody lost the ability to spell. Without spell-check on computer I would look a retard. Spelling was the first thing I noticed before struggling with sentence construction, written and oral. I now avoid many friends as I cannot engage in conversations where I'm processing what has been said and by the time I have unravelled it, cannot provide a response that is in context.

Patrick - OT:

It is a shame you feel you have to avoid friends in this way. Have you thought about explaining to selected ones about how you need bits of information and short sentences? It can be surprising how friends will adapt to your needs.

Nigel:

My friends are all aware of my problems with cognition and every aspect of my MS but, and this could be deemed a terrible thing to say, it would be a little like having Prof Stephen Hawking command troops in a close battle scenario. It just doesn't work.

I have lived in a world where lightening wit and repartee were vital and we still attempt dynamic conversation. It's frustrating for me but I also have to realise how tiring it can be for others especially when time is precious. I am friends with a number of people we see on TV some of whom have reputations for aggressive interview techniques. By narrowing or reducing contact time with friends I can stick to the tried and tested life of untrammelled tedium I inhabit rather than making myself ill attempting to follow a conversation that may as well be in Orc.

Creating structure to a sentence takes an eternity and I loose track of what I was to say. I quickly tire, start to slur and end up feeling as if my brains have been fried for a few days afterwards.

Patrick - OT:

Do you think there is an alternative to 'untrammelled tedium' which would not make you feeling ill? I mean different activities to pursue that might be more controllable within the context of you abilities but still satisfying?

Josie:

Sorry bit late joining page but I have been sleeping most of day. I went away at weekend and since I came back on Sunday afternoon I have done nothing but sleep, which is really annoying. I have things to do like sorting my desk out, putting photos in an album and writing Christmas cards but my concentration is non-existent these days. I just go from one thing to another then leave them all over. I hate the mess and it is just not like me I used to be so organised both at home and when I worked.

Patrick - OT:

First, if you are really fatigued then perhaps accept that you need to rest for a period. Next get a notebook and start to list the jobs in order of priority. Only do this for ten minutes and then rest for 20. Then do another ten minutes. At first this will feel really strange but by the end of the day you'll have something other than your frustration to show for it. If you really must start a job, then look at what needs to be done and plan to do part of it. For instance, if it is tidy the desk, then you are only going to tidy one bit of it or a single pile. Concentrate on the bit you've done not the stuff to do.

Josie:

Will the sleepiness go away? I am still tired when I wake up, even after a few hours deep sleep. Sometimes I have to close my eyes when people are talking to me but I can talk back and am aware of the conversation. It's just that I cannot open my eyes.

Jeffrey Gingold:

Josie's comments remind me how I use lists to have short-term and long-term goals for each day. The long-term goals frequently need to be broken up into steps, with breaks, but the list keeps me focused on doing something.

Josie, have you had any success with cap naps? I find that a quiet and controlled rest for 15 minutes does wonders to re-boot my energy.

Josie:

I do write lists Jeffrey but I'm afraid I leave them all over and forget to go back to them. Like if I'm out and think of something I write it in a note pad in my handbag, then when home leave it in there. I then think of some shopping I need, that list is in the kitchen, I then go to sit in my 'den' to have a rest, both lists forgotten about! Then it's the next day and I start all over again!

Shirley:

Yes, that sounds familiar. I also write out lists and have just found a load of previous lists whilst rummaging around looking for something else!

Lou:

I feel like that all the time too! I get distracted all the time and completely forget what I was meant to be doing - drives me mad!

Nigel:

A quick word of warning to 'friends' who are here who have found themselves getting lost/off track when driving. If this is happening in areas once deemed as part of your secure zone, stop driving now!

Keith:

Nigel, sensible advice. I found I went from driver to map reader to passenger in quite short time. Each move felt like a demotion at the time - male pride - but you get over it. Finding I couldn't read a map anymore (or at least quickly enough) was the big blow.

John:

Hi, most of the comments seem to relate to me! I get very, very tired by late afternoon and could sleep from 6pm - to 9am! I can't seem to get organised and I drift from one thing to another without completing either. I forget names and faces. All very frustrating!

Shirley:

I have also found these comments relate to me and I'm currently sitting in amongst a load of stuff which are on my 'to do' list. Very frustrating!

Jeffrey Gingold:

The best part of lists is crossing off the finished items.

John:

Shirley - Yep I up sitting at my desk at home with a big pile of 'to-dos' but have not done any of them yet! There is always tomorrow!

Patrick - OT:

Shirley and John, I would suggest your 'to do' lists are too long. Pick off the top job (check it doesn't need reducing into further 'chunks') and make a start for only five or ten minutes. Then rest for twice that time (and when I say rest that isn't 'change to a different task'). And then do another little bit. The littles will start to add up.

John:

I have 'to-dos' and 'tasks' set up on Outlook and I long for the day when they are all ticked done - I shall try your suggestion Patrick - thanks.

Patrick - OT:

John, try a 'sub-list' and then have a daily list that you transfer a realistic number of jobs too which then gets ticked and completed.

Sharon:

Jeffrey, thanks, I'll try lists going forward!

Josie:

Thanks for chat, its good knowing I'm not alone.

Lou:

Any ideas how I can improve my concentration and actually get things done rather than just adding more and more things on to my 'to do' list? I have two young children so resting and going somewhere quiet aren't really an option!

Patrick - OT:

You have to be brutal about priorities and ensure that all your activities aren't chores or obligations. If you overload your list, it gets very hard to do one job for the worrying about all the other stuff. So you have to start with the critical stuff, usually that's going to be childcare. This means there are going to be some areas you can't keep working at/on. So rather than looking at the dusting as a job, you have to say "that's not a priority and I am choosing not to do it". This way you have some control rather than feeling pushed about by an unfinish-able list.

If you find concentration difficult, break it up into short periods. Perhaps start at five minutes (no-one can concentrate for longer than 120 minutes!) and make sure you tell yourself that you've achieved five minutes NOT that there is another X minutes of work left in the task.

Jeffrey Gingold:

Hi Lou. I won't presume to understand your day, balancing needs of kids and normal tasks. However, I do think it is important to identify when you are most sharp and find a way to bring assistance to handle the kids at that point. If not able to bring in a friend or relative to help out, then maybe share this childcare task with another parent in the neighbourhood - who also needs a break. While this is challenging, I strongly believe that you need to take care of yourself too and find ways to rest your mind and body. Otherwise, the tasks pile up. Hope this makes some sense.

Carol M:

Can memory be improved by memory training activities? If it can, are there any publications that could help? I found that the books recommended on StayingSmart are an unknown quantity - ie without buying them all how do you know which one to buy? Is there one specific to MS problems?

Patrick - OT:

There is fairly limited research on the effect of training exercises on memory and what there is seems to show no effect. There was an article in Scientific American (see Resources section below), in a self selected population, where it doesn't seem to make a difference. Remember that may not be true for people who do have a cognitive problem when they start using the training.

However if it helps an individual feel they have some control over their circumstances then doing them can't be a bad thing. I think that practising tasks can be a good psychological boost and, like anything, people do get better at things through practice. If you want to use brain training then you certainly aren't going to hurt yourself and it is an occupation that can give structure to your day. If it were to cause frustration I'd advise not to do it. I am not aware of anything specific to MS.

Jeffrey Gingold:

While I can't speak to improving memory, I do believe that each of us with MS needs to stay active and mentally sharp. It is far too easy to withdraw from all activities and avoid contact which may highlight a cognitive problem. But that can start a nasty spiral of self-isolation and each person needs to identify for themselves what mentally challenges them and exercises their brain. The answer is different for each person.

Patrick - OT:

I agree completely - withdrawal and isolation on their own without MS would impair cognitive function.

Simon - MS Trust:

Jeffrey, as regards Carol's question about books on cognitive symptoms, and given that your own books on the topic are listed on StayingSmart, are there titles that you have personally found to be helpful or insightful?

Jeffrey Gingold:

I found that Dr Nicholas LaRocca's book, *MS - Understanding the Cognitive Challenges*, is an excellent discussion.

My second book, *Mental Sharpening Stones: Managing the Cognitive Challenges of MS* shares successful tactics from other MS people and medical providers. And of course, the newly released 2nd edition of my first book, *Facing the Cognitive Challenges of Multiple Sclerosis*, shares a path of acknowledgment of my MS

cognitive problems, learning a better understanding of the MS cause and how to best cope with the impediments for a vital life. It definitely is an on going process.

In case this sounds like a commercial for my books, please understand that all of my author royalties are directly donated to MS research and education. 100%

Simon - MS Trust:

Details of all of these books can be found in the Resources section at the end of the transcript

Carol M:

Can memory be improved by taking any form of medication, vitamins etc?

Patrick - OT:

Again I am afraid there isn't any evidence that there is an effect from diets or supplements. It would be lovely if there were! Similarly we have medications that can help manage some aspects of brain functioning, eg depression, but they are rather global in their effect. We still have a relatively poor understanding of how the brain really works (it is really, really, really, complicated) so the idea of a magic pill, whilst attractive, is very unlikely. It is possible as we learn how to manage the remyelination aspects of MS there could be a reduction in cognitive effects along side the physical ones.

Jeffrey Gingold:

I don't know what is available in the UK and appropriate for you, but I have had some success with Nuvigil - for sharpening my thoughts and raising my level of alertness. No real side-effects for me. Again, I am not a doctor, but just wanted to share what has helped me. Perhaps, ask your medical provider about it and see if it would benefit you.

Nigel:

In the first couple of hours of getting up, I am pretty much a cabbage and never stray from the same old, same old. I have been prescribed modafinil by my MS nurse in the hope it will act like prescription 'speed' and get me into action sooner. Does the panel have any comments on its use for this purpose? I ask because I have lost confidence in what has been prescribed to me without review over the last seven years. Using loperamide hydrochloride for almost seven years might well have masked bowel cancer. I am having a diverticulitis flare today and my temperature has just gone to danger point. Shame that nobody decided to look for other problems rather than bung me up as histology will be back this week so will have to remember to go to hospital! This is the element of MS that annoys me most. Changing my bed (twice last night), is p#ss easy compared with remembering to turn the washing machine on.

Patrick - OT:

Nuvigil seems to be prescribed for chronic fatigue and narcolepsy. I think if something works for you then that's fine. The difficult bit is identifying which bit of the effect is the drug and which bit is the expectation of the effect of the drug. Some people have very strong placebo responses. I haven't come across this medication before and it may not be licensed in the UK to treat MS.

Simon - MS Trust:

Nuvigil (armodafinil) is a development of modafinil, which is available in the UK as Provigil. Modafinil is licensed in the UK to treat excessive sleepiness associated with narcolepsy, though is used off licence in treating fatigue with some people with MS. The effectiveness depends on the nature of someone's

fatigue - if excessive sleepiness is contributing to this, the drug can help. If not, it is likely to be less effective.

Jeffrey Gingold:

Just to be clear, I am not a doctor, nor prescribing any medication for others. Just answering a question, noting that taken in moderation - Nuvigil has had certain mental and energy benefits for me. Provigil was tried, but my stomach didn't like it much. With Nuvigil, I have not experienced any such problems, none.

Again, please consult with your medical provider to determine whether a medication is available and if it is appropriate for your situation. Ask specific questions and take care of yourself.

Vanessa:

Hi, Thank-you for this forum. I have been struggling with cognitive issues for some time and have been waiting for a referral to a neuropsychologist for two years. There is no service in my area and I have therefore been sent to a psychiatrist. My fear is that depression will be diagnosed as I know the two are and can be linked. As a patient I know the difference and have found my cognition does not change with my mood.

My biggest hurdles are immediate memory. I now feel a lot less intelligent than I used to be. I cannot process what I am reading with ease and it is getting worse. I used to love reading books but cannot do this easily anymore.

My worst and most frustrating symptom is clicking between internet pages. In the second it takes, I have completely forgotten what I was going to Google! I am aware fatigue is my biggest MS symptom and fear this will also be blamed.

I guess my questions are...

What definite tests are there to ascertain cognitive issues within MS?

Is the need for MS neuropsychology to determine the difference between MS cognition and other neurodegenerative conditions, eg onset of dementia?

I'm feeling a little lost and fast becoming frustrated and my inability to make my brain work and therefore interact with the world like I used to.

Patrick - OT:

Vanessa - I can understand your concern, but the neuropsychology referral and assessment doesn't mean you have a dementia. Cognitive difficulties in MS are mostly mild and inconvenient and are very, very different from a dementia. Not the same thing at all.

Vanessa:

Sorry, I didn't make it clear. I was not suggesting dementia and MS cognition were the same, hence my question as to why MS specialist is needed. The feeling of losing your ability to retain and process information is soul destroying and one of the horrible silent symptoms.

Patrick - OT:

The more information you have about the particular characteristics of your cognitive changes the better chance there is of having strategies to compensate for it, that's why they are asking the specialist to see and assess you. I agree completely that it is an awful position to be in and I am sure very frightening at times. What we can be fairly sure about is cognitive changes in MS don't happen or change quickly, very small consolation.

Sam:

Vanessa, I agree. In some ways, dealing with the invisible things such as fatigue and woolly headedness became easier when I needed a stick. People understand a stick and seemed more open to my other symptoms as well. Without the stick, people didn't understand why I had no stamina and forgot everything and (I felt) found me very frustrating to be with

Patrick - OT:

It's very true that the public seem to need visual signs that someone has a condition. I was once in the invidious position of advising someone to use a stick at work solely to remind the employer they had a right to adjusted work. I still feel bad that it was necessary to do that - fortunately my patient felt it was a reasonable way to make work easier.

Jeffrey Gingold:

Sam, that is an interesting observation. You are so correct that cognitive symptoms are stealth, but with a walking stick - it does bookmark for others that something is going on and assistance is used.

I walk with a stick (for balance and leg numbness) and it quite often enables others to ask about any difficulties. I use the discussion to chat about MS and the invisible 'thinking' challenges. Sharing the information helped them to better see of all of the MS.

Sam:

Thanks for your comments. Thinking back, the stick was perhaps liberating for me too in a way. I'd been battling the effects of MS and denying them to myself to some extent - both pros and cons in this approach. When I admitted I needed the stick and found that it actually made life a little easier, I found it easier to admit to the effects of other symptoms and to acknowledge these and not hide them away. The psychology of this condition is very strange :)

Patrick - OT:

I'd say the psychology of people is strange and fascinating.

Vanessa:

Sam, I do suffer from many invisible symptoms. Unfortunately this does play havoc with your reasoning and self worth - now compounded by the fact that media and government are making many feel like scroungers. Sadly I welcome the time when I have motor deficit as across the whole medical media field this is seen as acceptable disability.

Patrick, thank you. Understanding is key. The worry of a cognition problem can exacerbate the symptom in itself! Knowing the issues can at least take away the unknown. My cognition does not come and go but does not seem to be worsening quickly. It seems to be slow and insidious.

Sam:

Vanessa, I do agree about symptoms and media. Hope my comment didn't sound too glib and I did skip over a number of year's worth of low self esteem

Vanessa:

As for the use of a stick, I do feel so judged if I use it. Also I want to appear normal. It's not a great pulling tool!

However, when I am in a queue I panic. I get angry that there is a queue. Yet if I think, the reason behind this behaviour is because of my muscle fatigue/ stiffness then spasm.

So yours and Patrick's post has helped me realise that using a stick is OK. It's an explanation rather than a self pity tool, which I'm so scared others will judge it as.

I think the psychology of this condition is for all

Sheelagh:

I care for my husband, who has MS, and reading all your comments helps me to understand a bit better as to how it feels for him. I understand the frustrations and his memory loss. I also think you make a valid point as people view him differently when he has a stick. On the flip side of that, sadly to some others he becomes the lovely man with the MS rather just the lovely man.

Jeffrey Gingold:

Sheelagh, your husband is fortunate to have you on board and to perhaps remind him that you always value him, despite the MS. Extra hugs are nice too.

Lesley:

I agree with comments about needing a stick to make a point that I have a health problem. I even have to do that with my family some times! Difficult for me as I don't like using a stick unless I really have to.

Patrick - OT:

Have a really nice stick rather than anything basic. That way it'll be less of a stereotype. There are some very light, colourful ones available that can be matched to the colours you prefer to wear.

Jeffrey Gingold:

Excellent tip regarding the stick. I avoided the hospital looking cane and instead, found a walking stick made of cherry wood with a nickel handle. It seems to suggest that it is not a short-term use and that I am comfortable with it. Find something that compliments your personality.

Patrick - OT:

I've always felt just because you have to use something it doesn't have to look medical or basic, though that's the starting point in our NHS.

Jeffrey Gingold:

I strongly agree. Folks should make it functional and personal for themselves. Then they may be more apt to regularly use it.

Vanessa:

Thank you for all your help and advice today. I feel better knowing that these issues are very common. And relieved to know MS is a lonely old mind game. I will go and find a nice stick. It will save a packet on the neon sign "stop looking at me funny I have MS" I was going to get! He he

Lesley:

I often get information overload and my brain seems to say I need to sleep. This happens mainly in the afternoon and is sometimes linked to other symptoms such as heavy legs and stiffness in the back. After an hour's sleep, I feel groggy to begin with but then more alert. I presume this is MS related. Any tips to try and prevent this happening?

Patrick - OT:

Sometimes it can help to have a routine where you rest by the clock rather than waiting to be tired and then needing a long rest and recovery. I would suggest planning a rest in the early afternoon, ideally before being completely tired. Try resting for an hour and use an alarm to wake you after that time period. If this doesn't work, play about with the length of rest/sleep and it's timing but always use the alarm so it is a planned rest period the same each day. It could take several days to discover if there is an effect.

HLB:

I tried modafinil for fatigue but it did not alter my fatigue. Going on a fatigue management six week course did. Eight years later I still have to prioritise, pace, not attempt more than two things a day and generally be kind to myself. Resting helps me to have a functioning brain when I'm awake. Keep stress to a minimum and arrange appointments at your best time. Don't be afraid to ask for help. Keep smiling

Simon - MS Trust:

The MS Trust book *Living With Fatigue* may be helpful with this.

Jeffrey Gingold:

Lesley, I so agree with Patrick that you need to anticipate what tires you and learn get ahead of it. Once I feel dragging, it is often too late to save the moment. However, I know what event or time of day will wear me out, then I can better plan rest periods in anticipation of the extra stress load. If I wait until I am totally spent, then even three shots of espresso won't help.

Lesley:

Thanks Jeffrey. I am an espresso drinker too and find that the boost just doesn't do it! Sleep helps me recover but regular patterns of rest are what I am going to aim for.

Patrick - OT:

Lesley, before you change anything it may help to keep a diary of your activity and fatigue with times so you have a starting point to work back from to identify when you are getting tired.

Lesley:

Thank you Patrick, I will try that.

Carol Mc:

I am finding it difficult to know exactly why I suffer some of the symptoms. I do sometimes forget where I have put things and have difficulty finding words on occasions and have had concentration problems. I must admit that I have never put it down to MS, which I was diagnosed with in February 2010. Could it be MS or is it my age or something else? I am 51 and a number of friends of the same age suffer from similar symptoms. More frightening for me was the thought of it being Alzheimer's which my Mum suffered from age 55. The concentration problems, which I put it down to fatigue, are now minimal since I reduced my working hours.

Patrick - OT:

Don't fall into the 'trap' of thinking that everything is due to MS. We all get cognitive problems at times. I have a complete inability to remember names (I'll know the person), sometimes even of friends I've known a long time!

Anna:

Blaming everything on MS - isn't that tempting? But I find myself saying things like "Ooh, I forget the name... oh, that isn't because of MS, I've always been like that" or "that's because I'm menopausal, it's not the MS".

Jeffrey Gingold:

Blaming everything on MS may be a convenient answer, but it shouldn't be an end point. Acknowledging that there is a problem should be seen as a path for identifying a coping tactic that works for you. For me, I often ask people to repeat their name and then write it down with a reference point. It takes the stress off of my brain to remember those details - whatever the cause. Don't give up searching for a better way to connect the dots for yourself.

Sarah:

Not everything is MS. Sometimes it seems GPs forget we can get other things, and put all pain down to MS. I find pain makes my thinking worse. I also find depression and anxiety are terms used too freely. Sometimes it is frustration and at others grief at slowly watching my active life disappear. Grieving is necessary, then having let go it is possible to find new activities and relationships. And I think it is OK to be fed up at times, but it should not get written down on medical notes as depression.

I wish someone had been honest with me right at the beginning and told be straight - MS is a degenerative disease of the brain. Had I got that first time round I would have made different decisions and not wasted so much of my disappearing active life. Having said that, I'm surprised that it is possible to have a contented housebound life. But thank goodness for a computer

John F:

Help!!! I was diagnosed nearly four years ago with progressive MS, and I can honestly say my memory and attention span seem to have taken an almighty nose dive. I have books that I really want to read but after maybe half a page my mind starts to wander and I just can't seem to get back focused. Is there anything I can do to help myself?

Patrick - OT:

Try reading for very short periods - five minutes - and see if that helps?

Dawn - neuropsychologist:

Some people find that pacing helps, which means scheduling rests and breaks. Another trick is to remind yourself every few sentences what you have read, rehearse a summary of the content every few sentences. Then you have thought about everything twice. These tips might help you.

Jeffrey Gingold:

Have you noticed that there are better times of the day to read? I have also found that reading is best with only white noise in the background. I am too easily distracted by telephones, television, family questions and the door bell ringing, etc, etc. Minimizing mental diversions and good lighting has helped me to focus on my reading. Taking breaks is also a benefit. Don't give up.

John F:

OK, will try. Also my neurologist has had me on a course of amantadine for fatigue for a while now and I don't believe it's as effective as it once was. Is there anything else that I could be asking to try?

Simon - MS Trust:

The MS Trust book *Living With Fatigue* may be helpful with this.

Elzbieta:

Is an increasing difficulty in recognizing people's faces an MS problem?

June:

I find my visual memory is better than my memory for words and names. I try and turn people's names into images - eg Robert Smith might become a blacksmith dressed as a robber, which sometimes helps me remember (though sadly not always).

Jeffrey Gingold:

I also find that repeating names and information out loud helps me to recall the detail much later. Perhaps, verbalizing the names and facts moves the information to the other side of my brain. Writing it down immediately is best for me.

Patrick - OT:

I'd agree completely the more and different types of senses used for information the more chance that it'll be remembered.

Justin:

Are there currently any practical steps that can be taken to reduce, or even reverse, cognitive deficits which have resulted from MS?

Patrick - OT:

Sadly no, there isn't a way of reversing the effects, just managing them. It is really down to strategies that compensate for the deficit someone has. Obviously a very stressed person has more trouble thinking but this is the stress effect rather than the MS.

Dawn - neuropsychologist:

There is some promising evidence from John DeLuca's research group that strategies for memory improvement can help. They have published a single centre study and given the results of a bigger multi centre trial at conferences.

The strategies seem to work best for people with MS who have moderate to severe memory impairment. Interestingly, it seems to be that reduced information processing speed is the underlying problem.

Lesley:

Dawn, the Research Group study you mention showing that reduced information processing speed is the underlying problem is exactly what I have experienced at times. Do you have a link or shall I just Google it?

Dawn - neuropsychologist:

I will send the abstract to Simon and it can be part of the transcript

Simon - MS Trust:

See the Resources section at the end of the transcript

Lesley:

Thank you. That is so helpful to know that given a little extra time in processing information can take the pressure off.

Patrick - OT:

Pragmatically, reducing the number of things to think about and increasing the time to do the thinking mean that someone with MS is just as accurate as someone without. You just have to arrange things in sequence and have time to consciously think problems through.

Darren:

I've just found out that I've got MS. The MS I've been told that I've got is relapsing remitting and I have been getting pains around my knees

Simon - MS Trust:

Hi, Darren. If you contact the MS Trust Info Team on infoteam@mstrust.org.uk or 0800 032 38 39, we'll try and help you find info about your symptoms and help you get in touch with your local MS nurse.

B:

Do you have any tips for coping with someone who denies they have any cognitive problems? My partner has an increasingly poor memory and is capable of leaving the door open or the cooker on, yet denies that this is the case or that anything is wrong. I'm worried about him damaging himself, yet can get no toehold on discussing the symptoms he denies

Dawn - neuropsychologist:

B, a lot of people face this challenge when loved ones have MS. It is usually best to tackle difficult issues at a relaxed time, not when the crisis or danger has just happened. Try to raise it from a context of your care and concern. If your partner continues to deny there is any problem, you might want to get professional help.

B:

He can be very stubborn. Could this be a lack of awareness of his situation? Could the MS do that to him? Or is it more likely him fighting against its effects by pretending they aren't happening?

Jeffrey Gingold:

Does your partner have a medical provider who understand the cognitive aspects of MS and do you attend appointments? If so, then that may offer a chance to share your concerns.

Possibly share an MS Trust factsheet about those symptoms with your partner. Part of the denial may include a concern that there is a piece of the mind that may be lost by acknowledging a cognitive difficulty. In fact, I believe that engaging the discussion is the best step to dealing with the difficulties and holding onto abilities. These things with MS never tend to get better all by themselves.

B:

Thank you - he does have an MS nurse, but I don't go to the appointments. Maybe I should get in touch

Jeffrey Gingold:

That would be a great start. This is not a matter of who is right or wrong - you are just concerned and sharing your observations with a professional. Hopefully, the MS nurse can take it from there.

B:

Thank you, that's reassuring.

Elaine:

Is insomnia something that is normally experienced by people with MS (it's something I have problems with)?

Simon - MS Trust:

Poor sleep can be one of the effects of MS - either directly or from other symptoms such as spasticity or continence issues that make it difficult to sleep through the night. We had an article on this in Way Ahead, our newsletter for health professionals, which you can read on our website (see the Resources section at the end of the transcript)

Susan:

I have periods where it feels my brain feels really foggy. Are there any tips for getting out of this? It makes the problem-solving decision-making parts of my job as a manager very difficult and I'm wondering whether I'd be better in another role.

Dawn - neuropsychologist:

You might find it helpful to talk this through with a professional. Do you know how to get to one?

Susan:

I've had a neuropsychology assessment. They advised pacing and rests to help with my cognitive problems, which do seem to help. But once I get this fog-like state it takes a while to clear. Just wondered if anyone had similar problem.

Dawn - neuropsychologist:

You might find the fog clears quicker if you try shorter work sessions.

Sam:

Do know what you mean, Susan. I think the advice earlier to take things in tiny steps and to do one small thing at once really fitted in with helping me through those periods - though it is far from easy to take on

Tracey:

I have primary progressive MS and although I tried very hard to keep up and be positive, I still find myself beating myself up about it. It would be nice to get info on how to cope.

Simon - MS Trust:

A previous chatroom looked at progressive MS. Maybe some of the comments in the transcript of that session will be helpful. The MS Trust also has a book called *Primary Progressive MS Exposed*, which may be of interest.

Jeffrey Gingold:

I am going to have to step away from the chat room for today. Thank you so much for the opportunity to share and learn from the MS community. Stay active and strong.

Sharon:

I have enjoyed this chat room and leave knowing that I am not alone with these weird and wonderful symptoms and thank God that I am still alive! Thanks all xx

HLB:

Very helpful. Glad to know I'm not alone in coping. Thanks to all involved.

Cheryl:

Thanks for your advice, this has been very interesting and extremely helpful reading what other people go through. The biggest battle for me is to get other people to understand what I go through, because I'm not in a wheelchair and look normal they think I'm lying. I suffer with most of what's been written today to some degree and the frustration of getting people to understand makes it so much worse. Thanks for doing these sessions.

Susan:

Thanks, this is all still very new and scary for me. It's good to hear that others have found ways that help with this.

Simon - MS Trust:

It's 7 o'clock so we have to come to the end of the chatroom now.

Thank you to Dawn, Jeffrey, Patrick, Jo, Fiona and Joan who shared their expertise throughout the day. And many thanks to all the people who have asked questions and shared their experiences of living with cognitive symptoms.

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

MS Trust Information Service

0800 032 3839 / infoteam@mstrust.org.uk

Books

- At work with MS
- Living with fatigue
- Primary progressive MS exposed

Factsheets

- Cognition
- Depression

Previous chatroom transcripts

- Cognition - April 2009
- Cognition - April 2005
- Progressive MS - September 2008

Open Door

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

- Can the monster shrink?
Jo Johnson
August 2008
- Staying cool with MS
August 2007

Way Ahead

Way Ahead, is the MS Trust's newsletter for health professionals

- Sleep disturbance in multiple sclerosis
Paula Cowan
Way Ahead 2011;15(4):6-7

All publications are free

Web pages

- **StayingSmart** - www.stayingsmart.org.uk
A website about the effect of MS on thinking
- **A to Z of MS** - www.mstrust.org.uk/atoz/
Brief information about a range of MS related topics
- **Map of MS services**- www.mstrust.org.uk/map/
Includes MS nurses and therapists and more
- **Work Toolkit**- www.mstrust.org.uk/professionals/work/
A resource for health professionals working with people with MS who are looking for help to retain or regain employment

Other resources mentioned

MS Society publications

- Shrinking the Monster by Jo Johnson
- MS Essential 02: Memory and thinking

These items are available from the MS Society - 0208 438 0799 / www.mssociety.org.uk/resources

Books

- David C Mohr
The Stress and Mood Management Program for Individuals With Multiple Sclerosis
OUP USA; 2010
0195368894
- Nicholas LaRocca and Rosalind Kalb
Multiple Sclerosis: Understanding the Cognitive Challenges
Demos; 2006
193260331X
- Jeffery N Gingold
Mental Sharpening Stones: Managing the Cognitive Challenges of MS
Demos; 2008
1932603654
- Jeffery N Gingold
Facing the Cognitive Challenges of Multiple Sclerosis. 2nd ed
Demos; 2011
1936303205

Mental Capacity Act

- Guidance and booklets about the Mental Capacity Act are available from the Ministry of Justice website
www.justice.gov.uk/guidance/protecting-the-vulnerable/mental-capacity-act/

CBT (cognitive behavioural therapy)

- Living Life To The Full website - www.livinglifetothefull.com

Brain training

- No gain from brain training
Scientific American; 20 April 2010

Papers mentioned by Dawn Langdon

- Goverover Y, et al.
Examining the benefits of combining two learning strategies on recall of functional information in persons with multiple sclerosis.
Multiple Sclerosis 2011; 17(12): 1488-1497.
- Sumowski JF, et al.
Retrieval practice improves memory in multiple sclerosis: clinical application of the testing effect.
Neuropsychology 2010; 24(2): 267-272.
- Goverover Y, et al.
A functional application of the spacing effect to improve learning and memory in persons with multiple sclerosis.
Journal of Clinical and Experimental Neuropsychology 2009; 31(5): 513-522.