



**National
Multiple Sclerosis
Society**

**MS Learn Online Internet Program
“Hold that Thought! Cognition and MS”
(Part One: Cognitive Changes)
2008 North American Education Program**

This food is good...

It happens to everyone, a missing word or phrase.

Where'd you get it? Um... Um...

It makes you feel disconnected with your own brain... and feel, like this woman, out of sync with the people around you.

But for some of us, it's more that the occasional memory stumble...
It's fairly common to hear people with multiple sclerosis complain of losing focus, getting lost or having problems remembering things. Concentration sometimes becomes extremely difficult.

And then there's the profound stress these difficult, widely reported MS symptoms place on relationships and self-image.

*We have a charity event tonight, tonight!
That's tonight?*

I have to work extra hard to try and stay on top of life. I tell myself, but you know that, and it's hard to realize that the motor is slowing down a little bit and that maybe I'm not as sharp as I used to be.

Yes, we all have MS moments. My husband and I can be having a conversation and suddenly I'm looking at him and he'll say, Donna, you there, are you listening? And it's, they're pauses, MS moments in time. Yes, and that's happened to me at work actually, which can be quite embarrassing. So, when that happens at work I usually excuse myself and say I need two minutes to collect my thoughts. With my husband, I just freak out.

It is frightening. Neural pathways damaged by MS express themselves in a wide variety of ways, but some of the most commonly reported symptoms are concentration issues and difficulty with memory. But hold that thought! In this program, we're going to investigate this phenomenon and provide valuable tips and techniques to help you manage many of the familiar cognitive challenges of MS.

Cognitive challenges are an invisible symptom of MS, in fact, just a few years ago, cognitive challenges weren't considered a symptom at all.

The whole issue of cognitive changes was really not focused on for a long time. In fact, patients were very often told by their doctors that MS did not cause cognitive changes.

Now, people are realizing more and more that cognitive issues not only exist, but they're very predominant. You'll see different studies have different samples, but in the clinical population you'll see about up to 70% of people with MS have some sort of cognitive issue. It's not that everyone has severe cognitive problems. Fortunately, most people have mild to moderate, but mild to moderate is enough to make it just difficult enough to ruin your day. You're trying to do something but it's just not quite working the same way, you feel like you're an alien brain, it just doesn't come out in the way you're used to it coming out.

Most people when they first read about MS will read about the fatigue, or they'll read about ways in which MS can affect their walking or their vision, and they need to know as well that cognitive changes can happen even as a first symptom of MS, when you're not looking for it or not expecting it.

If you catch something like this early on, you can address it, you can learn tricks to help yourself. You can learn to do things in a different way.

And learning how to do things differently is one of the most effective tools we have to address most cognitive issues. To get started, let's take a deeper look into the symptoms themselves. The most common complaint is trouble with memory

*My girlfriend will say, but I told you that, and I'll say, no you didn't.
"Tonight? Yes, honey..."*

I have a thought and it would just go away real quick. And I think wow, especially when I walk out the room, know I'm going to get something, I get there and I just stop in my tracks.

What's interesting from the current research is that we know that what a lot of people think of as a memory problem may really be something else. It may in fact be a problem with learning or absorbing the information in the first place.

For example, listening to a lecture, and the professor is speaking rapidly. If you can only process things slowly, you're not going to acquire that information as efficiently as you

would like. Therefore, when you try to recall it or remember it, you won't be able to do that well because you didn't learn it appropriately.

So we now know that if we help people with MS learn the information sufficiently to begin with, make sure they're not distracted, make sure they've had enough trials of learning it or hearing it, that they will remember it later. They'll remember it as well as people who don't have MS, but the trick is there that they really need to have enough exposures to that information or enough repetitions of that information in the first place to make sure it gets properly stored.

Another challenge is difficulty with attention and concentration.

I was medical laboratory technologist which involves a lot of multi tasking. You have to learn how to run all these tests together. I would run one and forget about the other one. I would run a routine patient and forget about the stat.

It was an HR department and it moved very quickly, and you had to stop on a dime and change direction and move to a different project. I started having problems with the switching.

If a person has trouble with complex attention tasks, they can't do multitasking any more, they can't pay attention well when several things are happening at once, they may miss something important that someone says to them, for example, because their attention is really elsewhere. Then, later, they experience it as not remembering that important information, but that information never got attended to or stored in the first place.

We'll spend some time a little later talking about ways to learn and store information more effectively, but first we'll describe some other kinds of cognitive problems, such as the visual spatial challenge – how we perceive the objects around us and our relationship to them.

Visual spatial problems are very common given how much, and it makes sense, how many times people have visual problems and visual disturbances. The optic nerve is a huge nerve that goes across the brain and has a lot of myelin. It gets attacked, it's involved in a lot of exacerbations. So often we see some visual repercussions to this, and this could be not necessarily the ability to see, but beyond that, once the information goes in, being able to do stuff with that information, being able to take the pieces we see and organize it together to make the whole. Being able to see where one thing is relative to another, which is very important to know where something else is like when you're driving a car.

I'd just walk in and just lose balance, sometimes trip over my feet... Thought I was just clumsy. And, but once I found out it was MS, now I know.

Very often what I'll hear is that they're suddenly, you know, feel like they don't know where body is in space, they're bumping into things more, and when you're already

having some difficulty walking, not judging where something is and hitting it and maybe causing a fall is an added difficulty.

Some people with MS experience problems with executive functions – that is, the ability to plan, prioritize, sequence, and execute goal-oriented behavior.

We see a lot of trouble with this disorganization, difficulty sequencing one thing after another, figuring out the most logical way to do things. We see problems with ability to shift from one task to another task and then shift back when they want to, problems maintaining thought if there's an external distraction or an interruption, problems switching between two people even speaking to them, doing two things at once. And very often, these are the things that are underlying just about everything we do in life.

So, these are the basic cognitive symptoms – challenges to memory and information processing, including difficulty with multi-tasking; problems with visual-spatial perceptions, where things are in relation to each other; and trouble with executive functions, such as planning, sequencing and problem-solving.

Now, the reason we're telling you all this is so you can see – and those around you can see – that these are real symptoms. You're not going crazy or losing it, even though you may not feel as sharp as you used to.

A lot of times persons with MS feel like their intellectual skills have been diminished, and in fact, intelligence is really not, is usually not diminished or affected in persons with MS. The feeling that people with MS have is that they can't, that intellectually they're not as good as they were before, but really what happens is, is that their rate of processing cognitive information may be slower, and because it's slower, the sense is that I'm not as intelligent as I used to be. It's very important for persons with MS to know that in general, intelligence is really not compromised.

For example, if someone has a great vocabulary and used to be able to use it a great deal, their intellectual self, that vocabulary, is still there. They'll know those words, it doesn't go away. But when they're speaking, perhaps they won't be able to pull out the word when they want it like they did before. So using their intellect becomes a little more problematic or using it the way they'd like to or they formerly did with ease.

The other area that's generally preserved is language. So the ability to actually receive language or understand language and the ability to actually speak or express language is generally preserved.

These cognitive symptoms we've been talking about don't exist in a vacuum. Many other things have an impact on them – depression, fatigue and our emotions.

There's a psychological aspect to cognitive problems in that one then feels less adequate in interacting in their environment, whether that's with their family or their employer or

with others, friends. So that feeling is important and is a subset of that actual cognitive problem.

When people begin to experience cognitive changes, it very often makes them anxious. And as we all know, when we become very anxious, it often interferes with our ability to function cognitively, and so you can have this overlay which actually exacerbates the cognitive changes.

The cognitive problems really do interact with how a person feels about themselves. If they're feeling like they're not doing as well as they could, now the cognitive problems and the impact are magnified.

And when people are depressed, and people who begin to experience cognitive changes will often become depressed because of that, when people become depressed it becomes difficult for them very often to utilize their cognitive skills and their cognitive strategies. So it's really important to make sure to get the help that's needed, the treatment that's needed for those emotional issues, not only because people feel better when they're not depressed or not too anxious, but also because getting those emotional reactions under control will then help the cognitive functions as well.

Often something that goes hand in hand with depression is fatigue.

MS fatigue, or fatigue and depression are evil twins. When one has to put so much more effort into doing everything, once again it's going to have this dampening effect on cognition. You're just not going to have their extra oomph. I like to call it diminished reserves. When we were younger we could all stay up all night and then the next day go to class and actually learn something. As we get older, we're less able to do that. When one has MS they're even less able, because their body is already working hard to compensate, to pull every reserve they have. They don't have extra reserve in order to help beat the fatigue in order to still then do things in the fashion they like. And then what happens, it feeds into depression, and depression feeds into the fatigue. If one is fatigued and can't get things done, it makes you feel depressed. If one is depressed and can't get motivated to do things, they start feeling fatigued.

But there's really not a lot of evidence to suggest that fatigue itself is actually diminishing the cognitive performance. That's a really important thing and the differentiation is important, that the sense of feeling fatigued is there and is real. The idea that it may be diminishing your ability to function or think clearly, it may not be.

And I see the way he was when I was growing up and how exhausted he was, and he would have to nap. I do that myself now. I see a lot of the same things my father did, I see myself doing. It's frightening. There's a lot about MS that's frightening, and the more you don't know...

I talk to people in my group. When they share things one of the things that I see is how very hard on themselves they are and that they have to learn to laugh. And that there are

certain things that they will lose, and you can be sad about those things, but you go on from there. You're alive, you have things going on in your life, there are many good things. You've sometimes just got to wiggle through the trees to find them again.

Of course, it's not just the person with MS experiencing stressful emotions – the family does, too.

One of the reasons that cognitive changes can produce a lot of stress in families is that it's so easy to misinterpret them. So a very common scenario might be a spouse saying to a partner with MS, "I told you that 3 times, don't you listen to me any more? Don't you care what I have to say?"

There were many times that I thought that she wasn't listening to me or that what I said she didn't feel was important, or when she tries to put herself down or something like that, it's just, yea, very frustrating sometimes..

You see a spouse misinterpreting a memory problem as a change in the couple's relationship, a change in how the person with MS feels about the relationship. We really, want to avoid that if possible because that quickly creates a huge amount of tension, resentment, sadness and anxiety.

One of the biggest things that is a stress reliever is communication. You may not want to talk, you may not always like the way you feel, but sharing it with your family, it takes the pressure off. It's like, it's like you see there and you go (sigh), it's like a big sigh. Yea, you feel a little better, you feel less pressured.

By labeling a memory or attention problem as that, the partners can begin to problem solve around it. If you have trouble remembering what I say, let's figure out together how we can communicate in a way that'll reduce that problem. Then I don't have to worry about whether you care about what I have to say any more, and you don't have to worry all the time that you're going to be forgetting something important.