

Staying smart and staying afloat



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To a casual observer it might appear that we are an ocean apart. When the MS Trust asked me to participate in a filmed group discussion, regarding the cognitive challenges of multiple sclerosis, the Atlantic distance between my home in the United States and London vanished. MS is not halted by a shoreline and neither are the efforts to cope with it.

In fact, those of us living with multiple sclerosis are sitting next to each other in the same boat, enduring stealth cognitive slams from MS lesions. Since at least half of the MS population is faced with thinking difficulties, there is no reason to remain silent on the turbulent ship. There are mental life jackets, but each person with MS needs to find the one that fits them. Discovering what keeps an MS mind well connected begins with acknowledging thinking difficulties and then learning successful coping tactics, often from others in the MS community. Were you told to handle MS setbacks by yourself? Probably not. Wouldn't you ask for directions in a foreign city and rely on those who know the way? There is nothing wrong with letting someone else drive, just like taking a taxi.

Arriving in London, I realised that my loss of presence in an MS cognitive moment is very much like experiencing a taxi ride in London. En route to the hotel for the MS Trust presentation, our driver noticed our American accents and asked if we enjoyed driving on the 'other side' of the road. My daughters, Lauren and Meredith, were thrilled by the experience of the driver sitting on the right side of the vehicle and driving on the left side of the road - backwards to us.

I chose to not contemplate how I would safely operate a car in this mirrored existence and gladly accepted the assistance of the driver to navigate the streets. To the gleeful squeals of our girls, the driver stated "but you prefer to drive over here, don't you?" He playfully careened the taxi into the right lane and zoomed toward the on-coming cars. Just short of sending the terrified traffic onto the sidewalk, he cut back to the left lane. My cognitive moments are like that, suddenly forgetting what I am doing or losing my place in a conversation or location, finding myself on the 'other side' of the road and unsure what to do next.

Group discussion

On that warm, blue sky day in June, they came from across the country and battled trains and Tubes to share their MS cognitive experiences. The MS Trust had recently launched its cutting-edge website www.stayingsmart.org.uk as an open invitation for the MS community to 'learn, build and share' a better cognitive understanding. This interactive site would assemble the best techniques to handle the MS cognitive challenges that are privately experienced by people with MS.

Make no mistake about it - there is an invisible stigma about cognitive challenges. It is difficult for people to move out of their initial denial phase when they are not educated about that part of MS and their doctor won't go there. If that discussion never starts, then the patient is caught in a circle of denial, leading to more denial. As I sat down for the presentation with a microphone clipped inside my shirt collar, the cameras began to roll and I wondered whether the attendees would run silent and slip into that denial. When asked whether anyone had any tips or tricks to share, the outpouring of personal cognitive skills began to flow. Collectively, they kicked open the door of MS cognitive discussion.

“Lists are very good, lists and lists and lists,” said a woman, as she emphasised keeping track of thoughts, as well as remembering where the lists are placed for future reference. Another woman stated that when cognitive problems began for her, she was unsure whether it was simply related to her fatigue.

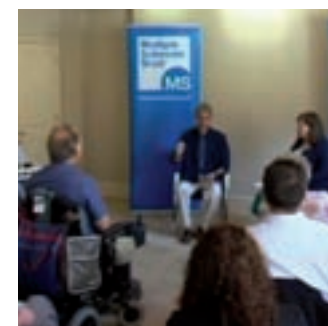
“When I was diagnosed,” said another lady, “I had a very stressful job where I had to spin a lot of plates.” It had become commonplace for her to lose the thread of a thought, leaving her with “a horrible, sinking feeling.”

Even though I was thousands of miles from home, the conversation mirrored the MS community in my neighbourhood. Those who are coming to grips with mental impediments are surprised to learn that they are not alone in their word finding difficulties, loss of concentration, mental fatigue and other untimely cognitive symptoms. Actually, it is a crowded room.

“You think that you're just imagining it all,” stated another man with MS. The concerns were real and the level of honesty was astounding. He noted that “to lose being a ‘thinker’ can be the scariest thing about MS. Heads in the room began to nod in strong agreement. Others discussed the loss of short-term memory and the methods for delegating tasks to other people, whether at home or work. More head nods.

Wanting to keep those bewildering cognitive moments to yourself tends to make matters worse, especially when others can't see the mental shutdown. Whether the word is caught on the tip of your tongue, conversations are confounded or you lost a train of thought, others may not understand the cognitive derailment. The jammed process is invisible, except for the frustration registered on your face. When it is taking you more time to accomplish less at work or on home projects, simply because you feel overwhelmed by multi-task details that were once manageable, this is also your MS, but you are not alone. Many of us dealing with MS have been there too.

A lady stated how her husband is far more patient now that he understands why she suddenly changes subjects in the middle of a conversation without even being aware of it. By sharing her experiences with MS cognitive misdirection, their relationship avoids collateral damage.



StayingSmart



There is a new safe harbour to address your concerns, which will place the maps and tools in your hands to better navigate the cognitive turmoil of MS. When you look into your private soul, discover that you are at your best when you share and help another. That is the purpose and appeal of this website, since it is designed to help any person with MS to get their thoughts back on track. In this vast and confounding ocean, the steady boat is the MS Trust and the calm port is its new *StayingSmart* website for cognitive discussion. Know that whatever cognitive problem that you may face, there may already be an answer addressed by others who have already landed there.

That day in London, many individuals from the MS community reached out with an honest discussion. Their personal coping strategies are all there on the site and the video clips are easily accessible to the MS community at large. They are brave to open their private stories and share their mental sharpening techniques, so that others dealing with MS might benefit from the on-point direction - hold fast to a vital life with your families and friends.

Whether in MS high seas, calm rivers or running against the tide, check out the cognitive sharing in your midst and begin to enjoy the benefits of sitting next to each other - smooth sailing and stay smart.

Jeffrey Gingold is an advocate for people living with MS and experiencing cognitive problems. He is the author of the books *Facing the cognitive challenges of multiple sclerosis* and *Mental sharpening stones: manage the cognitive challenges of multiple sclerosis*

Visit the *StayingSmart* website at www.stayingsmart.org.uk