

MS EMPOWERMENT SERIES

SHARED DECISION MAKING IN MULTIPLE SCLEROSIS



IS IT MY IMAGINATION, OR IS IT MS?

*Cognitive Challenges and Issues
for People with Multiple Sclerosis*



An educational series for people with multiple sclerosis (MS) developed in conjunction with the International Organization of MS Nurses (IOMSN)

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"I found myself avoiding conversations with family or friends, especially when I would hear the words, 'Do you remember..?' Not only was I embarrassed that I couldn't remember, I would panic because I was having problems speaking coherently. Cognitive rehabilitation has made a tremendous change in my life. It has taught me to use the tools from therapy to get around my limitations."

— KEITH R., DIAGNOSED WITH MS IN 1987

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Developed by Delaware Media Group in conjunction with the International Organization of MS Nurses (IOMSN)

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Hello, and welcome!

This brochure offers a brief overview to cognitive issues faced by people with multiple sclerosis (MS).



As a neurology nurse specialist for over 30 years, I have been privileged to interact with many hundreds of people affected by MS and their loved ones. I often feel that I am learning as much from my patients as they are learning from me! Becoming more informed about the condition and how it affects each individual is one of the most important parts of the relationship between the MS nurse and the patient and family.

This MS Empowerment Series was developed for the International Organization of MS Nurses (IOMSN) to guide the conversation between you and your MS nurse specialist or other healthcare professional. However, the conversation does not stop here. Every person with MS is unique and is affected in different ways. The ideas and resources in this brochure can be used to discuss your own needs and set goals for managing your condition.

I have been inspired by many individuals over the years who have faced and overcome the barriers they encounter. I hope these materials help to inform, guide, and inspire you.

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IS IT MY IMAGINATION, OR IS IT MS?

It can be a scary moment when you sense that your brain might not be working the way you want it to. Am I too tired? Is it an effect of the drugs I'm taking? Or, is my multiple sclerosis (MS) affecting my ability to think clearly?

Should I Be Worried?

As many as 60% of people with MS have some degree of cognitive change or impairment related to the disease. Fortunately, the problem is not severe in many people with MS. "Cognitive impairment in MS should not be confused with the types of deficits we see in people with Alzheimer's disease," explains Dorothea ("Dottie") Pfohl, an MS nurse specialist affiliated with The University of Pennsylvania. "A person with MS may struggle with some tasks, but we usually don't see a rapid downward slide into severe impairment."

Cognitive impairment does not always go hand-in-hand with severe MS. It can appear early in the course of MS, in a person who has few or no outward physical signs. The way it presents varies widely among individuals, just as other physical changes do.

Screening and Diagnosis

Many people feel they are somehow to blame for their cognitive changes. Others might think that nothing can be done to help them, or assume that diagnosing cognitive impairment



is a long and arduous process. Early recognition and diagnosis are important—for several reasons:

- The person with MS may be unaware of cognitive changes, but they could lead to problems in daily living (such as caring for children, commuting, maintaining a household).
- Cognitive problems are linked to job loss in people with MS, especially if they are not caught early.
- Effective treatments may be available that will help the person to manage or overcome some deficits. The treatment must be matched to the cause of the problem.

If you have MS, you might not be aware of subtle signs that family members or close friends might have noticed. Just asking if you have had difficulty concentrating or problem-solving may not be a good way for a healthcare provider to detect cognitive impairment. In addition, this cannot be determined by look-

ing at an MRI scan. But, newer screening tools are making cognitive changes easier to detect, even at a routine neurology or MS clinic visit. A screening test that takes as little as 10 minutes can indicate to a healthcare provider whether you should be referred for a more thorough evaluation.

Not all cognitive problems result from the MS disease process. In some cases they may be caused—or compounded—by issues such as stress, depression, fatigue, medication side effects, or even normal aging. (This should not imply that older people with MS are more likely to be affected: cognitive problems can occur at any age.) It is important to isolate possible causes before embarking on a treatment approach.

What Cognitive Changes Occur in People with MS?

Early signs of cognitive impairment include difficulty forming sentences or understanding conversation, difficulty remembering daily routines, and trouble with decision making. Some other examples are listed in the **Table** on the right. Although memory problems are common, not all types of memory are affected. For example, people with MS often retain long-term memory and procedural memory (remembering how to do something you learned long ago).

Treatment of Cognitive Impairment

Researchers are exploring new ways to slow, stop, or even reverse cognitive changes in MS.

Table. Cognitive Skills Commonly Affected in MS

Skill	Examples
New learning	Taking longer to learn a new task or skill
Memory	Forgetting appointments
Processing speed memory	Taking a longer time to “locate” existing information in the brain
Executive function	Difficulty making plans or problem solving, such as planning a vacation, or setting the week’s work goals
Multi-tasking	Trying to do too many things at once. This can increase confusion for anyone, but may be heightened in those with MS

Effective treatment with an MS disease-modifying therapy helps to prevent further damage to the brain. These treatments can slow brain cell damage and minimize MRI lesions. These benefits are thought to apply to cognitive changes as well as “physical” symptoms. Clinical trials of these drugs do not always look at cognitive changes, so more information is needed about their potential for helping cognition.

What to Expect from Cognitive Rehab—A Patient’s Perspective

When I was diagnosed with MS 30 years ago, I was in denial that anything could make me “weak.” I hid what symptoms I could and blamed other symptoms on something else. Then, in 2016, I experienced my worst MS relapse to date. No more denials!

This relapse caused havoc with my cognitive skills, mainly short- and long-term memory recall. I found myself avoiding conversations with family or friends, especially when someone said, “Do you remember...” I was also having problems speaking coherently. Common words evaded me—I could see the word I wanted in my mind, but I couldn’t articulate it. The words coming out of my mouth were not the words in my mind!

I finally put my ego aside and asked an MS nurse for help. Her reaction was supportive and non-judgmental. She just pointed out that I was avoiding a treatable issue instead of addressing it. She let me know I was not alone, and I was guided to a cognitive rehabilitation program that same day.

The cognitive therapist explained what I could expect. Memory issues are targeted, but also the planning and execution processes we use daily. The therapy can also help to stimulate and redevelop our problem-solving skills. I was told that, with a bit of education and effort on my part, I could recover a lot of what I thought was permanently gone. We started with some activities to set a baseline. The activities were not intimidating or overwhelming; they were actually amusing. They included recollection, reactions, and spontaneous responses to a variety of situations. Most involved dealing with day-to-day situations and demands. After each session, the therapist offered ideas and practices for improving my cognitive skills.

Cognitive rehabilitation has made a tremendous change in my life. It has taught me that any limitations I have may be just my own perceptions and not necessarily so crippling. Using the tools I learned, I can turn negative situations around. I highly recommend it to anyone with any cognitive issues. So, speak up—someone is listening.

— KEITH R.
DIAGNOSED WITH MS IN 1987

Certain other drugs—such as those used in Alzheimer’s disease—have been studied in people with MS, but the results do not suggest a clear benefit. Supplements like ginkgo biloba have also been studied, again with unclear benefits. If you do use dietary supplements, you should

always discuss them with your healthcare provider.

Cognitive rehabilitation

Cognitive rehabilitation is thus far the most successful approach to managing MS cognitive deficits. This form of rehab takes advantage

of *neuroplasticity*, which is the brain's way of "rewiring" itself to work around problems. In specialized MRI studies, different regions of the brain "light up" when a person with MS is performing a task, suggesting that new regions are being recruited by the brain to help make up for areas that might be damaged. Over time, the re-wiring can become permanent.

Cognitive rehabilitation can be practiced at home, at an MS clinic, or at a specialized rehab facility. Ideally, the program should be guided by a therapist who has experience with MS, since the changes in MS differ from those that occur due to stroke or other brain injuries.

Cognitive rehab can involve word games or puzzles specifically designed to help boost cognitive skills. Computer-based methods may be enjoyable because they add a game-like element to the task. According to one theory, people with extra "cognitive reserve" benefit

from cognitive rehab. "Cognitive reserve does not necessarily equate to high intelligence," Ms. Pfohl explains, "but perhaps to a 'lifelong love of learning' that promotes mental flexibility. The brain is a flexible, changeable organ, and almost anyone can benefit from cognitive rehabilitation, at any stage in life."

What about "brain training" games?

Commercial brain-training "apps" available online should not be confused with formal cognitive rehab. In fact, there is no conclusive evidence that brain-training apps are any better at preserving brain function than activities you might do on your own—such as reading a challenging book, doing word puzzles, or any mentally challenging task you enjoy. Having said this, any of these activities beat passive exercises like watching TV. If we think of the brain as a muscle, "brain training" can be a form of exercise to keep the brain healthier.





How exercise can build your brainpower

Recent research shows that physical exercise can boost cognition in people MS, especially in tandem with cognitive rehab. By this theory, exercise encourages the formation of new nerve cells, which are further strengthened by mental tasks. While this research is preliminary, it stands to reason that exercise can enhance memory and help slow cognitive decline. Along with its potential cognitive benefits, exercise has been shown to decrease fatigue, anxiety, and depression, and enhance quality of life in people with MS.

Support systems

Participating in a support group can be especially helpful, since many people feel they are facing cognitive challenges alone. Peer support offers the opportunity to exchange coping tips, share personal experiences, and give voice to the frustrations a person often faces when living with MS.

Teaming Up with an MS Healthcare Provider

Should you speak up, or just try harder to work around the mental “fuzziness?” You might be surprised to learn how many others have been in your position and found ways to address cognitive changes in MS. Refer to the resource list on the next page, and talk to your MS nurse or other MS care provider.

RESOURCE LIST

Resource	Source/Contact Information
Multiple Sclerosis Association of America (MSAA) Jeri Burtchell's blog provides a realistic depiction of how cognitive changes have impacted her life.	www.mymsaa.org > Living With MS > MS Conversations Blog > Search: Jeri Burtchell 800-532-7667
Multiple Sclerosis Foundation (msFOCUS) "9 Strategies to Deal with Cognition Problems" Straightforward tips to reduce effects of cognitive change on daily life.	www.msfocus.org > Publications > MS Focus Magazine > Search: 9 Strategies 800-225-6495
National Multiple Sclerosis Society (NMSS) Presentation by a psychologist and physical therapist talks about benefits of physical exercise on cognition.	www.nationalmssociety.org > Living Well with MS > Cognitive Health > "Your Mind is a Muscle, Too" 800-344-4867
LiveWise MS "Brain Food" article discusses how diet affects brain health and impact on cognition.	www.livewisems.org > Resources Journal articles > Brain Food
LiveWise MS Check out this site for more on how physical fitness affects cognition.	www.livewisems.org > Resources > Journal articles > "The Influence of Cognition Impairment on the Fitness-Cognition Relationship"



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