

RealLiving WITH MULTIPLE SCLEROSIS

Cognitive Problems: Research and Real People

by Laurie Stoneham

Most people with MS accept that they can't always rely on their bodies to work properly. J.W. Dillingham has not trusted hers for more than 20 years.

Not being able to think straight, though, can be alarming, frightening, and embarrassing. J.W. knows. She first noticed the changes in her work as a computer programmer.

"I started making errors and had trouble following through from start to finish. I'd lose my train of thought or enter a word that had no relevant meaning, and the program would bomb."

J.W., who scores in the 98th to 99th percentiles on IQ tests, says the problems may have been creeping up on her for a while, but she only began noticing them in January of this year, in the midst of a major exacerbation. "My memory was all screwed up. Names of people I've met in the last year are lost temporarily or permanently gone. I used to have a semi-photographic memory; I could tell you where something was located on a specific page. Now I'm lucky if I can remember what book it's in."

Some perspective

What's happening to J.W. is relatively common in people with MS. Studies conclude that between 43 and 65 percent of all MS patients have cognitive problems - Difficulties with memory, thinking, perception, and/or language.

Knowledge and interest in cognitive changes is fairly recent. While cognitive changes in MS were noted well over a century ago (Charcot described them), most doctors believed that MS manifested itself only in physical disability, leaving the mind unaffected in most cases. In 1980, that perception began to change based on the advent of magnetic resonance imaging (MRI), autopsy data, and neuropsychological findings in MS research. In the intervening years, much has been learned about how MS affects the way the brain operates.

Stephen M. Rao, Ph.D., a clinical neuropsychologist and Professor of Neurology at the Medical College of Wisconsin in Milwaukee, is one of the country's experts in this area. (Dr. Rao also serves on the Editorial Advisory Board for Real Living with Multiple Sclerosis.) Much of what is known has been the result of studies Dr. Rao has initiated. We spoke with him by phone. Dr. Rao explains the field of neuropsychology as "the study of brain-behavior relationships-how behavior changes when the brain is affected by disease or trauma."

As with all MS symptoms, changes in mental capacity are highly unpredictable. "We see stability over long period of time. Some patients may get cognitively better or worse, depending on whether the amount of brain lesions decreases or increases over time," Dr. Rao explained. Similarly, there is no way to predict if or when the brain will be affected. "It could be seen, from the very beginning of the disease," Dr. Rao told us. "Or the onset of cognitive symptoms might come late in the course."

Also, Dr. Rao has found that there is little, if any relation between physical disability and cognitive impairments. Someone who has severe physical limitations may think clearly, while the person with no outward signs of MS may have serious cognitive impairments.

What is known

Studies have shown that persons with chronic/progressive or relapsing/progressive MS generally perform more poorly than those with relapsing/remitting disease.

In his research, Dr. Rao has also discovered links between cognitive impairment and other aspects of life. In a recent MS Management article, Sr. Rao wrote that "...cognitively impaired patients with MS are less likely to be employed, engage in fewer social activities, and require greater personal assistance than cognitively intact patients."

J.W. went on disability in late April. She and her doctor decided it was the only thing for her to do. "My cognitive problems were very bad. I was all stressed out, and my physical problems got worse, too."

Divorced shortly after her diagnosis in 1988, J.W lives alone in the Denver area. She'll be getting a service dog this fall to help with daily living tasks.

The role of depression

One of the myths that is slowly being dispelled is that people with MS have memory problems that are caused solely by depression.

Nicholas G. LaRocca PhD, Director of Training and Research at the MS Center at St. Agnes Hospital in White Plains, New York, explains, "In severe clinical depression, transient intellectual changes occur because the mental processes are slowed. Most people with MS don't have depression that causes these profound problems." (Dr. LaRocca also serves on the Editorial Advisory Board for Real Living with Multiple Sclerosis.)

He goes on to say that anti-depressants may offer a lift so that people may function better and be more satisfied with their lives. However, D. LaRocca points out that "anti-depressants will not wipe out, or even significantly change cognitive problems."

The causes

Recent MRI studies have shown that there is some relationship between the total number of MS lesions and cognitive dysfunction. It is known that mental processes are affected if MS lesions are found in the brain, and the exact location of these lesions may relate to what cognitive functions are impaired.

There is evidence, for example, that people who have lesions in the frontal lobes have difficulty making decisions and solving problems. A different pattern of cognitive impairment has been seen in individuals who have thinning in the middle of the grain in an area known as the corpus callosum.

Finding out for sure

Like everything associated with this symptom, assessing impairment has undergone some change. It is now known that the formal mental status test called the Mini-Mental State Examination (MMSE) is insensitive in detecting the types of cognitive difficulties that people with MS experience. While this is the standard test for Alzheimer's and other forms of dementia, Dr. LaRocca said, the MMSE misses about 50 percent of the problems in MS patients. It's not sensitive enough to pick up the subtle changes."

Professionals agree that completing a battery of carefully chosen neuropsychological tests is the only way to know for sure what is causing cognitive difficulties in people with MS.

According to Dr. Rao, "These are thorough psychological tests used to evaluate specific functions of the brain such as memory, attention, information processing, and reasoning."

There are some downsides to these tests, however. First, they can be quite expensive, ranging from \$300 to \$1000, and may take up to eight hours to administer. And they must be administered and interpreted by properly trained neuropsychologists.

Dr. Rao and other professionals have identified the need for a brief cognitive testing instrument that can be given by non-neuropsychologists to distinguish between cognitively impaired and cognitively intact MS patients.

There are some other options to a full neuropsychological battery that, depending on the patient's need, may be helpful to supplement Dr. Rao's Neuropsychological Screening Battery for MS. For example, speech/language pathologists may use a battery of formal cognitive and language measures that takes about two hours and costs between \$300 and \$400.

Testing the brain

J.W. wanted to do whatever was necessary to find out what was necessary to find out what was happening to her brain. With the help of her neurologist, she has had a series of tests.

The first was a psychological profile to rule out depression. That came up negative. Three EEGs looked at her brain wave patterns. Results from two of those tests were abnormal, the third was normal.

"The doctors thought I might be having seizures or strokes, so I had a test to measure the optic nerve." That was normal, too. Finally, the 47-year-old went through eight hours of neuropsychological testing, the results of which were not fully known at the time of publication. "We're looking at a person's thinking patterns," Dr. Rao explained. "We're essentially creating a profile of an individual's strengths and weaknesses. From there, an analysis can be made as to how to work around or compensate for the persons "impairments.""

Treatments

At this time, there are no known treatments for cognitive problems, only rehabilitation programs. This may change in the near future.

Promising results were achieved in a very small study using an intravenous form of a medication for Alzheimer's disease known as physostigmine. Oral administration of the drug was not as positive.

A clinical trial is now underway at the Cleveland Clinic's Mellen Center for MS Treatment and Research to evaluate what impact, if any, Cylert® (used to treat fatigue in MS) has on cognitive function. And according to Dr. LaRocca, anecdotal reports indicate that the experimental drug, 4-aminopyridine (4-AP), may be beneficial, but there have been no bona fide clinical results or any published studies supporting these claims.

Therapy

Cognitive rehabilitation for MS is more widely available today than five years ago. Dr. LaRocca advised that MS patients can find this kind of support at most rehabilitation and teaching hospitals that treat head injury and stroke victims. Many major MS centers also offer this kind of therapy. The rehab team is made up of a psychologist, speech/language pathologist, and occupational therapist, Dr. LaRocca told us in a telephone interview. "It involves the direct training of the memory by challenging it with exercises. The second phase is compensatory, devising strategies for overcoming problems."

J.W. admits all of this has been scary and frustrating for her. "it makes me more scared about the future. I wonder if I'll be able to take care of myself. I cried a lot at first."

"I've had to learn to readjust my lifestyle-avoid things that frustrate me-and learn to relax. Before when I'd lose a word or a thought, I'd get really tense, and the more tense I was, the worse the problem would be. Now I stop, take a breath, and find a different word."

She goes on, "The one thing I was always able to rely on was my brain, so I could get things done. I could always get a job. I still have a lot of skills, and my hope is that I can get enough retraining so I can go back to work, at least part-time."

Dr. Rao believes, "People function well when they have enough information about their disease. That's why a good diagnosis is so important and then one can design an effective plan for overcoming deficits and building on strengths."

What's not affected

While short-term memory may be impaired, other memory functions are spared. For example, research has shown that the ability to detect differences in the meaning of words remains unchanged. Implicit learning - being able to learn new information or skills without actually using the knowledge - is also generally not impaired.

What is called "simple attention span", the ability to concentrate on simple tasks, is also believed to remain intact.

Some Management Strategies

Here are some ways to compensate for cognitive impairments.

Consistently write important things down each day and keep your notebook with you. J.W. keeps her notebook in a fanny pack she wears all the time.

A tape recorder may be helpful for the same purpose, especially if vision and writing are difficult. Become meticulously organized. Live by the adage, "a place for everything and everything in its place."

Keep a big family calendar. This way everyone knows what everyone else is doing, where they're supposed to be and so forth. Make it a priority to have this complete and up-to-date. Have family members share in the responsibility.

If you frequently forget you have something on the stove, keep a timer in plain view and get in the habit of using it whenever you cook.

Timers or alarm clocks can also remind you of appointments and or times to take medication. Attach a Post-it-note that reminds you what you are to do when the buzzer sounds. Computerized information managers are excellent organizational tools.

If you have trouble processing information, avoid situations that demand on-the-spot decision-making. Learn to tell others what you need: "A little slower please," "Say that again" or "I'm with you up to But I have a question about"

In work situations, a private office may enable you to concentrate better without interruptions. Be open and talk to your employer about making changes for you.

Let the people you live with and work with know that your disease is having an impact on the way your mind is processing information.

Follow J.W.'s philosophy: have a sense of humor; have a sense of creativity to learn new ways of doing things and always, always have hope.