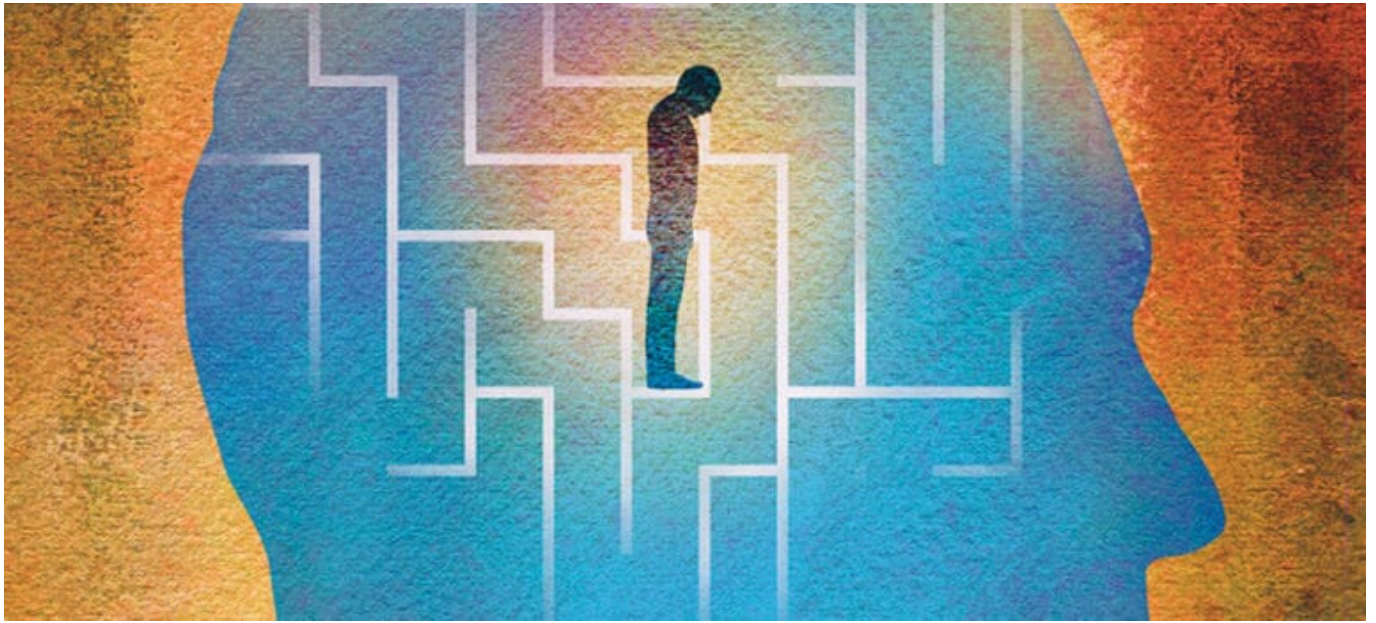


A closer look at cognition



Cognitive function screening can identify problems and help improve treatment for people with MS.

by Brandie Jefferson



A cognitive assessment helped Diane Kramer pinpoint a treatment plan to improve her memory and better focus on the activities she enjoys. Photo courtesy of Diane Kramer

In hindsight, there were plenty of clues that multiple sclerosis had affected Diane Kramer's cognitive function.

She was diagnosed in 2010, but it would be four years before a doctor verified cognitive impairment.

In the interim, she remembers all sorts of little things that suggested something wasn't right.

"Little things," she says, "that feel so much bigger."

Re-washing clothes because she couldn't remember if she had put detergent in the machine. Getting lost while walking her dog. She even stopped cooking because it was becoming increasingly difficult to follow steps in a recipe.

Researchers estimate about 60 to 70 percent of people diagnosed with MS will face some level of cognitive impairment. Although it has only been since the mid- to late 1980s that the medical profession has understood this connection, there is now a suite of treatment options available to help people mitigate the effects and regain control over their lives.

"Until the 1960s and '70s, maybe even later, medical students were taught that cognitive problems were not a feature of the disease itself," says John DeLuca, PhD, senior vice president of research and training at Kessler Foundation. "In the '70s it was thought that only about 3 percent of people with MS had cognitive problems. We know today it's up to two-thirds of people."

The research may be clear, but it's still not easy for many people to get the support they need.

When Kramer was diagnosed, her doctors discussed long-term therapies, medications to deal with symptoms—and wheelchairs. "My second doctor said I'd be in a wheelchair within a year," she says. No one suggested she might also have to deal with difficulty remembering things, getting lost or losing her temper.



**John DeLuca, PhD,
says that a formal**

assessment is the best way to identify a specific cognitive

issue. Photo courtesy of John DeLuca, PhD

Cognitive screening is rare

That's not surprising. A 2012 Consortium of Multiple Sclerosis Centers member survey found that 52 percent of healthcare professionals who worked with people with MS said that they did nothing at all to screen for cognitive function, and 19 percent asked patients about cognitive issues, but did no formal testing. "You can see where patients can get frustrated," DeLuca says. "It's time for patients to get the help they need."

For Kramer, that started with "self-referring" herself to a new hospital in a different state. The Pennsylvania resident made an appointment at the Johns Hopkins Hospital in Baltimore. At the time she was working full time as a nurse in a small cosmetic surgery office.

The doctors were accommodating, letting Kramer nap midday and take time off as needed.

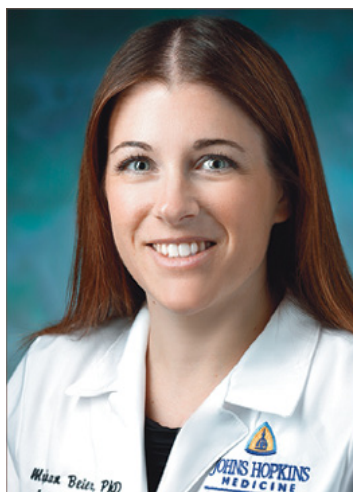
But in the spring of 2014, things happened at work that a nap or a day off couldn't fix. Kramer walked into a room to set up machinery that she'd used plenty of times before. "All of a sudden, I had no idea what I was doing," she says. Then she recalls co-workers commenting, "Let's see how many times she says, 'Now I know I put that right here.'"

Just as she was going to talk to her boss about her problems, Kramer was called in for a meeting. Her boss told her that in responses to a survey, "People are noticing you're getting distracted, abrasive, and you're getting frustrated and blowing up at other people."

Noticing changes in behavior

Who hasn't walked into a room and forgotten what they were looking for or spent too much time looking for keys? While there is no definitive way to know if any individual lapse in memory is related to clinical impairment, Kramer experienced a telltale sign that it was time to seek help.

"Most people, all people really, are pretty bad at judging their own cognition," says Meghan Beier, PhD, assistant professor of physical medicine and rehabilitation at Johns Hopkins Medicine. What is more accurate is if friends, or family or coworkers are starting to notice changes, Beier says.



**Meghan Beier, PhD,
advises telling your
neurologist about any
cognitive changes.**

Photo courtesy of
Meghan Beier, PhD

When that happens, Beier suggests a person do what Kramer did and tell their neurologist. “If people are wondering about symptoms, don’t brush them off.”

Kramer’s doctor referred her to Abbey Hughes, PhD, who specializes in neuropsychological assessment, cognitive rehabilitation and MS rehabilitation. Kramer underwent a comprehensive cognitive assessment, which included tasks that evaluated not only memory but also her ability to learn and store information. The evaluation included tests on information processing speed and the status of her executive functioning abilities, which include paying attention, organizing and regulating emotions.

A formal assessment is important because, according to DeLuca, studies have shown a typical neurological exam, done in the course of, say, a six-month checkup, is no better than chance at identifying a specific cognitive problem in people with MS.

Comprehensive assessment

“The No. 1 complaint is memory,” he says, but often for people with MS, the problem may not be memory itself, but other aspects of cognition such as processing speed or executive functions. “Say you are listening to a lecture. If your processing speed is slowed down, you’re not going to learn as well. When you try to remember what you heard, you say, ‘I don’t remember.’ But that’s because you didn’t learn it to begin with.” A comprehensive assessment can pinpoint exactly what kind of impairment a person is dealing with, allowing healthcare providers to prescribe a more focused treatment.

Kramer found out that she did, in fact, have cognitive impairment. “What a relief it was,” she says. “Now there was a very clear way I could start working on it.”

That would not have been the case just a few decades ago. “At first, there were no recommendations at all for treatment,” says Jeffrey Wilken, PhD, professor of neurology at Georgetown University Medical Center and director of the Washington Neuropsychology Research Group. “Now people realize that there can be interventions.”

Interventions range from medications to help focus, to looking at whether specific disease-modifying drugs have a positive impact on cognition, Wilken says. Recently, Wilken says more providers are turning to cognitive rehabilitation programs.

These programs are aimed at understanding what impairments a person is dealing with and then working to either strengthen those areas or compensate for them. For example, if a person is having difficulty remembering something she has read, she can strengthen her ability to retain information by “space training”: reading a passage three times, spaced 10 to 15 minutes apart. “Simply by adding that space,” DeLuca says, “people learn better and, consequently, remember information better.”

Much of Kramer’s therapy has focused on behavior modification to compensate for loss of function. “I need routine, if I get off that routine, things become difficult,” she says. For instance, to make sure she takes her medications correctly, she makes a note each time she takes a pill, and her husband fills her pillbox.

To help her in the kitchen, she says, “I print out recipes and put them inside a plastic protector and cross off things as I go. It’s just small little deviations. You feel so smart when you come up with them.”

Some changes come from her rehab specialist, with whom she checks in every three months.

In fact, Kramer, DeLuca, Wilken and Beier say anyone with MS could benefit from a cognitive assessment as a baseline against which they can compare their ability down the road. At Hopkins, for example, Beier says processing speed tests are now performed at every visit.

In a paper published in the *Multiple Sclerosis Journal*, DeLuca and co-authors outline guidelines for cognitive treatment that have been recommended by the National Multiple Sclerosis Society.

They include a baseline cognitive screening assessment and an annual re-evaluation screening.

Access to screening

For many people, however, getting these tests won’t be easy.

DeLuca says that patients who visit large clinics or university hospitals may be more likely to have access to comprehensive cognitive screening. Right now, he says, “I am not sure that most people will see this at their local neurologist.”

“This should be something that a patient expects,” DeLuca says, “but there are two big challenges: Are there enough people trained in cognitive rehab and familiar with MS? The answer is no.

Will insurance pay for this? The answer right now is, generally no. Some will, but in general, treatment for MS is poorly insured.”

In addition to insurance coverage, various factors affect the price of an exam. “Whether it is being done at a hospital or a clinic or a private practice, whether it is being done by the psychologist or a testing technician,” Beier says. “Also, region of the country matters. For example, an assessment in Maryland would likely be less than in New York City.” Add in the varying lengths of assessments and Beier says, on average, the price could range from \$1,200 to \$5,000.

For the near term, the good news is that recent research shows simple tests can give neurologists an overview of their patients’ cognitive abilities. “We’re finally seeing some very simple screens looking promising,” Wilken said. “The Symbol Digit Modalities Test is a short, 90-second screen that can help neurologists determine whether someone might have a problem.”

In the longer term, DeLuca says, cognitive screening will have to be an advocacy issue for patients, clinicians and societies “to get insurance companies to pay for these tests, and to make sure they are available to everyone who needs them.”

Kramer has been stable for several years now. Despite her previous doctor’s projection that she’d be using a wheelchair, she ran the Hershey Half Marathon in 2012, and completed three 150-mile Keystone Country rides. Shortly after she was called in by her boss, however, she stopped working in the office. She applied for Social Security Disability Insurance and receives full disability benefits.

Kramer may not go into the office, but she is constantly working. “I work very, very hard at maintaining the life that I do,” she says. In addition to volunteering at her daughter’s school, she easily puts in five hours a day of various cognitive therapies.

“I truly am optimistic. You can change the way things are going. For MS, we don’t have something like blood sugar that you can read and say, ‘Yes, I did good today,’” Kramer says.

“It’s being able to live a better life on good days. That is the way you measure success.”

Brandie Jefferson is a freelance writer in St. Louis, Missouri. She was diagnosed with MS in 2005.

Find resources and more information about [cognitive changes](#).

Find more information about [recommendations for cognitive screening](#).