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Lost in thought:

## When cognition changes

PAGE 36

## A great education with MS

PAGE 29



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**On the cover:** Claire Flaherty doesn't let MS get in the way of her education.

## departments

- forward 3**  
Cyndi Zagieboylo on moving **Momentum** forward
- @momentum 7**  
Readers sound off on art, diet and a cure for MS
- pulse on MS 9**  
Are you ready for the Affordable Care Act?
- move 51**  
DIY fundraiser: A ghoulish garage
- fired up 52**  
Lurching with enthusiasm
- impact 56**  
Tyler Campbell: Going for the tackle
- this is me 64**  
The lessons of MS

## features

### thrive

#### A great education with MS

A spectrum of strategies can help people with MS achieve their educational goals. **29**

#### Lost in thought: When cognition changes

MS can affect memory and thinking, but the right techniques and tools can help. **36**

### connect

#### When the caregiver has MS

People with MS share tips on caring for their loved ones—and for themselves. **42**



Mark Somerfield shares a humorous take on managing his MS.

# 52

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## Lost in thought:

# When

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## changes

by Leslie E. Silverman

**J**effrey Gingold was a litigation attorney in Milwaukee in 1996 when he began experiencing overwhelming fatigue—not just physically, but mentally as well. Diagnosed that year with multiple sclerosis, he began to have trouble concentrating, remembering details and making decisions. “One day in court I turned to look at my client, and suddenly I didn’t know who she was or why I was there,” Gingold, now 53, recalls. “I didn’t want to make mistakes that damaged my partners or clients. When I left my practice in 2001, I walked out the door physically, but cognitively I still had a real problem.”

While Gingold’s experience represents the more severe end of the cognitive dysfunction spectrum, challenges with concentration, memory, organization, planning, reasoning and judgment are common in MS. Nicholas LaRocca, PhD, vice president of Health Care Delivery and Policy Research at the National MS Society, estimates that up to 60 percent of people living with MS experience some degree of cognitive deficits, or “cog fog,” as those who live with the problem sometimes call it.

Cognitive difficulties can occur at any time in the course of the disease, or not at all, Dr. LaRocca says, and they can affect seemingly simple tasks, such as remembering the grocery list, as well as complex activities like organizing a project at work. MS-related cognitive difficulties fall into three categories:

**1. Attention.** Staying focused on the task at hand can become difficult. Multitasking and dividing attention are even more problematic.

**2. Memory.** People have trouble remembering names, recent conversations, appointments and sequential information, like driving directions. But long-term memory is typically not affected, Dr. LaRocca says.

**3. Executive functioning.** A healthy brain enables people to plan, organize, solve problems and make strong decisions. With MS-related cognitive dysfunction, these processes become especially challenging, particularly when considering multiple sources of data. Driving, for example, requires you to be aware of traffic signals, other cars, pedestrians, weather conditions, etc., and to use the information to make ongoing, rapid-fire decisions.

### MS and cognition

Neuropsychologist John DeLuca, PhD, vice president for research at the Kessler Foundation Research Center, says an overall slowing of processing speed caused by MS is one mechanism that can lead to cognitive dysfunction. “If you’re accustomed to processing everything quickly, like a state-of-the-art computer, and now your speed becomes more like an old 286 processor, it’s going

“

**If you’re used to functioning highly, even subtle cognitive deficits can have a big effect on you.”**

to take a lot longer to get the same answer.” Dr. DeLuca emphasizes that cognitive dysfunction in people with MS does not necessarily translate into impaired intelligence. In fact, cognitive changes may go unnoticed by others. “If you’re used to functioning highly, even subtle cognitive deficits can have a big effect on you,” says Steve Rao, PhD, a neuropsychologist studying cognitive dysfunction at the Mellen Center for Multiple Sclerosis at the Cleveland Clinic.

### Facing depression

Cognitive symptoms are sometimes masked or worsened by co-existing problems, such as depression and chronic pain, explains Pavle Repovic, PhD, a neurologist at the Multiple Sclerosis Center of the Swedish Neuroscience Institute in Seattle.

In fact, some people with MS may initially attribute cognitive difficulties to depression, but a good multidisciplinary team can tease out what’s causing them, Dr. LaRocca says. “Depression can be accompanied by slowed thinking, difficulty concentrating and memory lapses. However, these are likely to resolve if and when the depression lifts. Cognitive changes that are a result of neurological changes are likely to progress in severity. Cognition can improve in some cases if the cognitive changes are a result of inflammatory changes associated with an exacerbation.”

Medications used to treat pain in MS can also cause cognitive dysfunction. “Some studies of patients undergoing long-term opioid treatment for chronic pain have shown adverse effects on attention, speed of information processing, working memory and short-term memory,” says Dr. LaRocca. Dr. Repovic adds that some medications commonly prescribed for bladder dysfunction (Ditropan, Detrol, Vesicare and Enablex) can contribute to memory loss, somnolence and confusion, although these effects typically occur more suddenly than when they are MS-related.

### Finding what works

Detecting cognitive problems is helpful only inasmuch as therapies and strategies are available to manage them, however. “The search continues for a pharmacological solution to improve cognitive dysfunction,” says Dr. LaRocca. A medication used to treat memory and other cognitive problems in Alzheimer’s disease generated some early excitement about possible use in MS, but the research didn’t pan out. “Double-blind, placebo-controlled studies of stimulants haven’t been as promising as we’d like, either,” he says.

Behavioral treatments can improve function, however. “People with MS can substitute strategies for memory, like using an iPad or smartphone calendar,” Dr. LaRocca says. Calculators, online maps and GPS units, voice recorders and even old-fashioned pen and paper can also help people deal with cognitive challenges. “It’s not ‘improving memory,’ but creating workarounds for tasks that demand memory,”



Dr. LaRocca says.

Gingold learned some of those workarounds the hard way, so he wrote a book, **Facing the Cognitive Challenges of Multiple Sclerosis**, to share coping strategies. When engaging someone new in conversation, he explains that he may respond slowly after he processes information. “I don’t want people to think I’m ignoring them, or that I don’t care,” he says. “I ask people to give me information in small bits so I can digest it first.” He also asks people to email him information, because he knows he can’t listen to details and simultaneously write them down. “I pretend it’s because I have bad handwriting,” he says, laughing.

Gingold keeps a positive outlook and remains focused on adapting to his changing cognitive abilities. “I’ve learned to better organize myself, cut a lot of the mental and visual clutter that was distracting. I avoid large gatherings where I can’t focus on one conversation at a time. And I listen to more jazz and less rock, because I must quiet things down,” he shares.

### The therapeutic approach

Speech-language pathologist Licia Paskay, MS, CCC-SLP, says Gingold’s approach is exactly right. “Paying attention helps you store the memory in the first place,” she says.

In CogniFitness, a program that Paskay and her colleagues run for the Society in conjunction with the Marilyn Hilton MS Achievement Center at UCLA, “we help people become more aware of distractions and manage them,” Paskay explains.

With attention under control, people can focus on improving memory. Dr. DeLuca says one technique is to space learning episodes over time. Another method is to “self-generate” information you want to remember by periodically testing yourself about it. Sometimes you can combine both approaches. For example, if you’re trying to remember when you have a doctor’s appointment, study it on your calendar several different times during the week (spaced learning). “That reinforces the encoding of the information,” Dr. DeLuca explains. Then bolster it with self-generation; family can help with this, too. “If you

have an appointment on Friday, have a family member ask you to retrieve the information the Sunday before. On Monday, they can provide hints to help you retrieve the memory again, saying, ‘There’s something you have to do Friday. Do you remember what?’ If you can self-generate the response, then it’s more deeply encoded in the brain,” Dr. DeLuca says. Even further, his research shows that associating information with specific imagery and also adding context or meaning to the information significantly improves learning and memory in MS.

While researchers and clinicians acknowledge that working on such skills in a therapeutic setting can be effective, the jury is still out on the use of popular home-based computer “brain training” programs, like Lumosity or BrainHQ.

A 2011 study found that people who used Lumosity for 20 minutes a day for five weeks had significant improvements in visual attention and working memory. However, the authors had a financial interest in the outcome, and the number of people studied was small (25). And, as Owen, et al., the authors of a 2010 study published in the journal **Nature**, point out, “The central question is not whether performance on cognitive tests can be improved by training, but rather, whether those benefits ... lead to any general improvement in the level of cognitive functioning.”

To answer this question, Owen and colleagues



Find tips and memory aids at **stayingsmart.org.uk**.



Watch a video interview with Dr. DeLuca at **Momentum MagazineOnline.com.**

conducted a study of more than 11,000 people and found no evidence for any generalized improvements in cognitive function following computerized “brain training.” The field is still in its infancy, however, and more independent research is needed.

When it comes to improving or compensating for impaired executive functions, Paskay and her colleagues emphasize the importance of preparation, and teach CogniFitness participants how best to use reminders and alarms to aid planning.

“You need a coach, just like with physical exercise,” says Dr. DeLuca. “You need someone familiar with MS and with these interventions. Comprehensive MS Centers should have lists of qualified neuropsychologists and speech-language pathologists that patients can go to.”

Such specialists can help you plan for the inevitable “mental jam,” too. That’s crucial, because the worst time to talk about a cognitive challenge is while it’s happening, says Gingold. That just heightens anxiety, making the cognitive problem feel even worse.



Call an MS Navigator at 1-800-344-4867 for referrals in your area.

### Social studies

Anxiety and impaired recall, reasoning, problem solving and judgment can affect interpersonal relationships, too. Los Angeles resident Susan Selbrede, 48, diagnosed with MS in 2009, was chief financial officer of a business she ran with her husband until pain, fatigue and cognitive dysfunction made it impossible to work. “My communication was impaired, too,” Selbrede says. “I think because of my cognitive issues I really pushed a lot of people away.” She credits the CogniFitness program for enabling her to communicate and begin to repair business and personal relationships.

“Don’t beat yourself up for not being who you used to be,” Selbrede advises others. “It’s important to

keep socializing and seeing friends.” That’s true, even if it means keeping gatherings small, so you can follow the conversation. In fact, Dr. DeLuca says studies show that keeping socially and intellectually active improves brain function. “I tell patients, ‘Get out of the house, read a book a month. Then get someone to ask you what you read about. Build stimulation into your life. That’s your therapy—it’s not a pill!’”

### Moving forward

Drs. DeLuca and Rao agree that more thorough cognitive assessments of people with MS are necessary. “We do MRIs for physical symptoms, and we need as thorough an evaluation for cognitive symptoms,” Dr. DeLuca urges. Otherwise, the more subtle cognitive symptoms are likely to go undetected. “And patients don’t mention cognition unless you really ask about it,” Dr. Rao says.

Dr. Repovic and his colleagues at the Swedish Neuroscience Institute are creating a detailed online questionnaire that patients will be able to complete before their appointments, giving neurologists a better sense of how much fatigue, depression, anxiety and cognitive challenges are troubling them. The Cleveland Clinic is working toward a similar system using tablet computers, and hopes to roll it out to other healthcare providers. “With the National MS Society funding our research, we’re validating our cognitive tests to make this app available to clinics worldwide,” says Dr. Rao.

Dr. DeLuca believes many neurologists are deterred from evaluating cognitive problems because they have no pharmaceutical solutions to offer. “They’re trying to be efficient and act where they can have an impact. If you’re having cognitive problems, discuss them with your neurologist and contact the Society for a referral to a neuropsychologist, occupational therapist or speech-language pathologist familiar with MS. They’re trained to help you come up with solutions.” ■

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Leslie E. Silverman is a Connecticut-based freelance writer. She was diagnosed with MS in 2007.

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