InforMS

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Rocky Mountain
Multiple Sclerosis Center

Brain Drain

MS cognitive problems are common, confusing, usually mild, mostly manageable and always draining.

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ROCKY MOUNTAIN
MS CENTER
— *the answers begin here* —

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RMMSC Mission Statement:
To improve the lives of people with MS and their families through care, support, education and research.

Cognitive Problems, Fatigue and Social Security Disability

by Thomas Stewart, M.S., J.D., PA-C

Treatments for MS are advancing rapidly. It is increasingly clear that more and more people with MS will never develop impairments that will interfere with their ability to work and many people with MS will never become disabled.

Even so, some people with MS remain at risk for disability. According to the Social Security Administration, MS is the third most common neurological cause of disability, behind only stroke and epilepsy. Of course, the consequences of unemployment related to disability are numerous, but for those with a sufficient work history, two of these problems–poverty and lack of medical insurance–are partially addressed by Social Security Disability Insurance (SSDI).

> MS is the third most common neurological cause of disability, behind only stroke and epilepsy.

Contrary to recent media reports, it is not always easy for people with MS (or other chronic diseases) to obtain these benefits. Of those who apply for disability benefits, only 37% nationally are successful with their initial application. Additional claims are allowed during the appeals process—approximately 50% of the minority of claims that are appealed—but the appeal process is time consuming and stressful.

Some people with MS will find the SSDI application process straightforward. This group of people will generally have good access to medical care and have well-documented impairments, such as severe gait impairment (e.g., using a walker or wheelchair.)

The majority of people with MS will have a more difficult time. This is especially true when the primary disabling conditions are fatigue and cognitive problems, which are among the most commonly disabling MS symptoms.

The problem for applicants with fatigue and cognitive problems is that the typical neurological examination is not designed to assess these symptoms in detail. Thus, many people with MS who are unable to work because of cognitive difficulties and fatigue may have a normal or near-normal neurological examination reflected in their medical records. This matters because their medical records may not provide objective evidence of their most significant impairments. An applicant without objective evidence of disability will not receive disability benefits.

Although neurologists generally assess mental status, they do not routinely perform the detailed cognitive testing that is usually necessary to identify specific work-related difficulties. Nor do neurologists always refer patients for detailed cognitive testing. For those with cognitive difficulties that may limit employment, referral to a neuropsychologist may be useful to develop the kind of information necessary to prove MS-related disability. For those with fatigue, referral to occupational or physical therapy may be helpful. In any case, specific support from your treating neurologist will be critical. Remember to report your cognitive difficulties to your neurologist at each visit.

If you are in the process of applying for Social Security benefits, you should obtain expert legal counsel at any stage of the process. The Rocky Mountain MS Center offers a free consultation, and, where appropriate, representation to people with MS nationally. If we can help you early in the process, there may be no charge for representation.

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AMPYRA should not be taken with other forms of 4-aminopyridine (4-AP, fampridine), since the active ingredient is the same.

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What is the most important information I should know about AMPYRA?
AMPYRA can cause seizures.
- You could have a seizure even if you never had a seizure before.
- Your chance of having a seizure is higher if you take too much AMPYRA or if your kidneys have a mild decrease of function, which is common after age 50.
- Your doctor may do a blood test to check how well your kidneys are working, if that is not known before you start taking AMPYRA.
- Do not take AMPYRA if you have ever had a seizure.
- Before taking AMPYRA tell your doctor if you have kidney problems.
- Take AMPYRA exactly as prescribed by your doctor. See "How should I take AMPYRA?"

Stop taking AMPYRA and call your doctor right away if you have a seizure while taking AMPYRA.

What is AMPYRA?
AMPYRA is a prescription medicine used to help improve walking in people with multiple sclerosis (MS). This was shown by an increase in walking speed.

It is not known if AMPYRA is safe or effective in children less than 18 years of age.

Who should not take AMPYRA?
Do not take AMPYRA if you:
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- have certain types of kidney problems
- are allergic to dalfampridine (4-aminopyridine), the active ingredient in AMPYRA

What should I tell my doctor before taking AMPYRA?
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- are pregnant or plan to become pregnant. It is not known if AMPYRA will harm your unborn baby. You and your doctor will decide if you should take AMPYRA while you are pregnant.
- are breast-feeding or plan to breast-feed. It is not known if AMPYRA passes into your breast milk. You and your doctor should decide if you will take AMPYRA or breast-feed. You should not do both.

Tell your doctor about all the medicines you take, including prescription and non-prescription medicines, vitamins and herbal supplements.

Know the medicines you take. Keep a list of them and show it to your doctor and pharmacist when you get a new medicine.

How should I take AMPYRA?
- Take AMPYRA exactly as your doctor tells you to take it. Do not change your dose of AMPYRA.
- Take one tablet of AMPYRA 2 times each day about 12 hours apart. Do not take more than 2 tablets of AMPYRA in a 24-hour period.
- **Take AMPYRA tablets whole. Do not break, crush, chew or dissolve AMPYRA tablets before swallowing. If you cannot swallow AMPYRA tablets whole, tell your doctor.**
- AMPYRA is released slowly over time. If the tablet is broken, the medicine may be released too fast. This can raise your chance of having a seizure.
- AMPYRA can be taken with or without food.
- If you miss a dose of AMPYRA, do not make up the missed dose. Do not take 2 doses at the same time. Take your next dose at your regular scheduled time.
- If you take too much AMPYRA, call your doctor or go to the nearest hospital emergency room right away.
- Do not take AMPYRA together with other aminopyridine medications, including compounded 4-AP (sometimes called 4-aminopyridine, fampridine).

What are the possible side effects of AMPYRA?
AMPYRA may cause serious side effects, including:
- serious allergic reactions. Stop taking AMPYRA and call your doctor right away or get emergency medical help if you have:
  - shortness of breath or trouble breathing
  - swelling of your throat or tongue
  - hives
- kidney or bladder infections

See "What is the most important information I should know about AMPYRA?"

The most common side effects of AMPYRA include:
- urinary tract infection
- trouble sleeping (insomnia)
- dizziness
- headache
- nausea
- weakness
- back pain
- problems with balance
- multiple sclerosis relapse
- burning, tingling or itching of your skin
- irritation in your nose and throat
- constipation
- indigestion
- pain in your throat

Tell your doctor if you have any side effect that bothers you or that does not go away.

These are not all the possible side effects of AMPYRA. For more information, ask your doctor or pharmacist.

Call your doctor for medical advice about side effects. You may report side effects to the FDA at 1-800-FDA-1088.

How should I store AMPYRA?
- Store AMPYRA at 59ºF to 86ºF (15ºC to 30ºC).
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Keep AMPYRA and all medicines out of the reach of children.

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This Medication Guide summarizes the most important information about AMPYRA. If you would like more information, talk with your doctor. You can ask your pharmacist or doctor for information about AMPYRA that is written for health professionals.

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Active ingredient: dalfampridine (previously called fampridine)
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THERAPEUTICS

An Interview with Jeffrey Gingold

Coming Out of the Cognitive Closet

by Bridget Blanning

Jeffrey Gingold is an outspoken volunteer advocate on MS and cognitive disability and the internationally acclaimed author of the award-winning book, *Facing the Cognitive Challenges of Multiple Sclerosis.* He spoke with the Rocky Mountain MS Center's Bridget Blanning about his personal cognitive challenges, what keeps him mentally active, and the power of volunteering.

Q: Jeffrey, you are a tireless advocate for people with MS, and have focused on the need to recognize and address cognitive challenges. Please tell us about your own journey with MS and how it brought you to where you are today.

A: My interest in MS cognition was born out of an absence of information for people living with MS. When I encountered some thinking and memory problems—right after I was diagnosed—I thought I was losing my mind. It was devastating. I was a litigation attorney, so I decided to retire. At that time, there were no MS patient references available. The doctors didn't seem to accept that "thinking" problems had anything to do with MS, and there was a stigma with admitting you had a thinking problem. No one seemed to be treating it or talking about it, but I refused to believe that I was alone with these problems. I figured if I started talking about it maybe other people would also come out of the "cognitive closet."

Q: In 2006 you wrote a book about your own MS cognitive challenges—*Facing Cognitive Challenges of Multiple Sclerosis*. In essence, you paved the road for better understanding and open discussion of the cognitive effects of MS. Tell us about taking on that pioneering role.

A: I knew that by talking about something like this, and perhaps being one of the first people to do so, there was a risk of people not understanding. But I had looked through hundreds and hundreds of MS books and there were no discussions of the cognitive aspects of MS for people to recognize and understand in themselves. Zero. I didn't know where I was going with it, but I knew that MS was never going to go away by itself and neither were the cognitive difficulties. I learned that a ship that's taking on water can either put out a mayday signal for help or silently go to the bottom of the sea. I didn't want to sink—to lose myself or my family and just disappear quietly in the MS. I wasn't going to do it.

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From left to right: Lauren, Terri, Jeffrey and Meredith Gingold on vacation in London, summer, 2012.

I think anyone enduring MS and the cognitive symptoms can benefit from sharing their challenges. I came to realize that by speaking about MS cognitive matters I wasn't alone in dealing with them. In fact, more than half of people with MS silently endure these symptoms. As I toured with the first book, I had people come up to me and say, "You too?" Then they would tell me about their challenges and many of them mirrored what I was experiencing. They told me that after reading the book, they were better able to articulate their experiences to family, friends and medical providers. *Mental Sharpening Stones*, my second book, came out of those conversations. People wanted to share their successful tactics—how they lived with the challenges, what they discovered, what coping mechanisms they developed.

I always like to mention that the royalties from my books all go to MS research and education—100 percent. My motivation is to use education about the disease to fight the disease.

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Gingold

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Q: Many people who experience cognitive challenges talk about the frustration and tension that can arise both internally and with their friends and loved ones. In your experience, what can help alleviate these feelings and strengthen relationships?

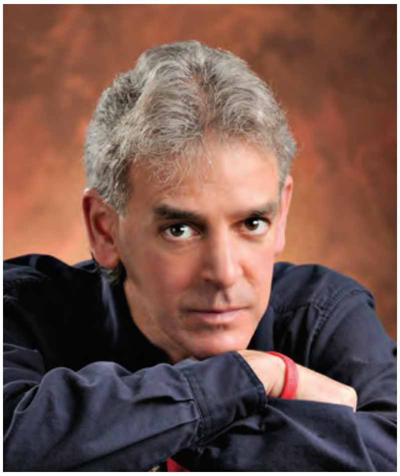
A: I often recommend that people get this on the table before problems happen. I believe that the worst time to try to explain a cognitive moment is when it's happening because you may be drowning in mental confusion. If you give friends, family, co-workers, neighbors or relatives examples of what it can be like for you and things they can do to help—such as get you to a safe and quiet place, make sure you're in a cool environment, things like that—you empower them. Together, you can develop a game plan. I think that others are part of the solution, not the problem. If you keep it from those around you, you're making it difficult for them and for yourself—and it doesn't have to be that way.

> There are very few things that are so powerful as allowing someone to help you.

There are very few things that are so powerful as allowing someone to help you. Reverse the situation: how would you feel if you saw a friend or relative struggling and you knew you could do something. Would you want to stand silent and walk away or would you—if they've given you the tools to help—want to jump in and do something? Let them know what they can do because they're going to want to help.

Q: For you, what coping strategies are helpful in dealing with cognitive challenges?

A: A couple things that I heavily rely on are, one, not taking myself too seriously and realizing that I can't and don't have to do it all by myself. There are people who are informed about my difficulties and very willing to step in and help. Second, I write notes to myself and I'm constantly organizing and reorganizing. I can't carry all the information in my mind like I used to, but I now know where to get it all. This helps organize my thinking and routines and reduces mental clutter. For example, we like to have lists in our house for the hardware store, grocery store, clothes shopping, and activities for the day, week and month. These list items don't have to be done at once, but when I come up with an idea, "Oh, I need coffee creamer," I don't have to get it right then. All I have to do is put it on the list and then I can forget about it. That simple organization helps declutter my thinking.



Q: What do you think are helpful forms of regular mental stimulation and activity? What works for you?

A: I tend to believe that there isn't one thing that works for everyone, because if it doesn't excite or interest a person they may grow bored with it in a very short period of time. Everyone has to identify what most stimulates their thinking. For me, I still enjoy writing. Whether it's articles, or continuing to work on other book projects, it keeps me active. Reading is very stimulating, as long as it's a book I want to read. I like to focus on one thing at a time; that really helps me. Another thing that I find very mentally stimulating is exercise. I can't do certain pre-MS things such as running, but I find the exercise I can do makes me feel sharper and more engaged. It's important for people to find something that is stimulating for them. Anything that gets their minds and hearts pumping is likely to help.

Q. Since retiring from your law practice, you have created a new normal for yourself, which you describe in the book. What's been key to building that new normal?

A. I'm not the first to have discovered that one of the keys is volunteering. I volunteer for various MS organizations. It's an amazing experience to come face to face with people who are willing to open up and share. You're mutually helping each other and it's very empowering. Sometimes you won't know the effect of volunteering, and you don't need to, but it's out there and it only happens if you take the first step. If it helps someone, it makes it all worth it. For me, that's the best reward: to discuss and positively affect someone's life so that they can help themselves. And extra hugs, too. ■

Jeffrey Gingold's books, *Facing the Cognitive Challenges of Multiple Sclerosis* and *Mental Sharpening Stones: Manage the Cognitive Challenges of Multiple Sclerosis*, are available at www.amazon.com.

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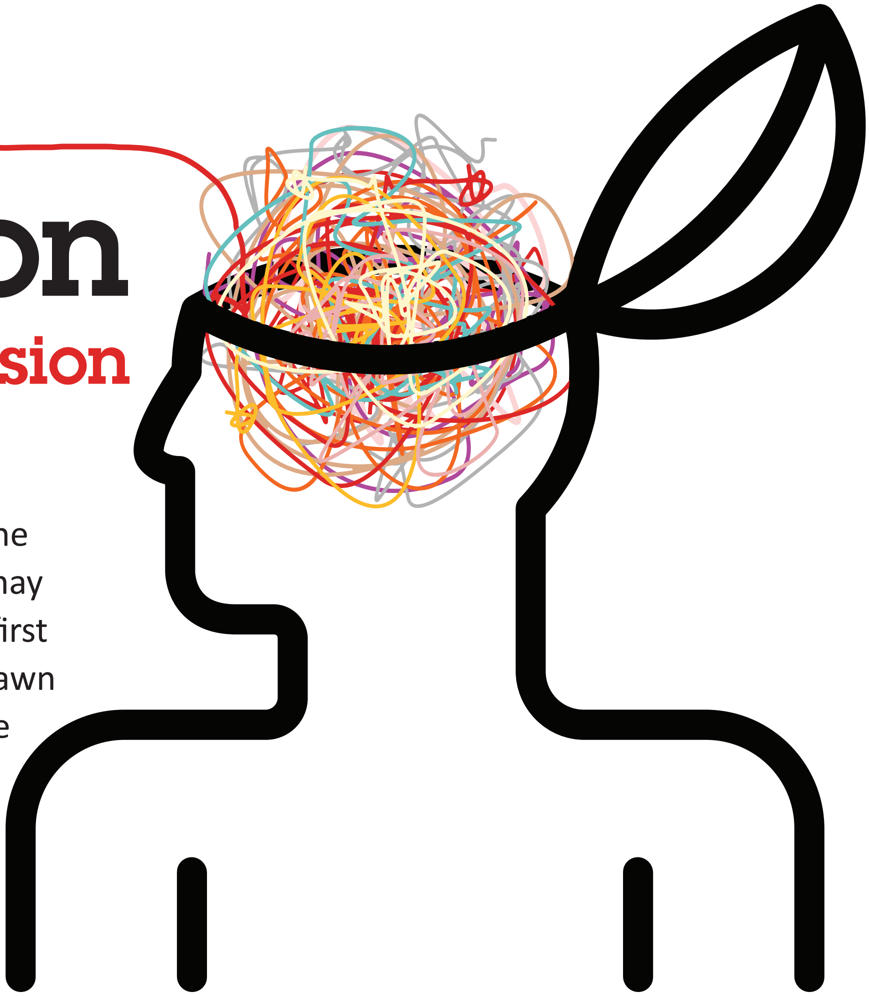
Cognition

The Ball of Confusion

by Patricia Daily



Most people with MS worry about the future—but what they worry about may change over time. When people are first diagnosed their attention is usually drawn to the most visible symptoms of the disease and one of the biggest worries, early on, is that they might loose the ability to walk. When someone has had MS for a while, though, they become more aware of the subtle and invisible problems that MS can cause and the focus of their worries may change. Recently, a person who has had MS for ten years and is now struggling with some cognitive problems remarked, “When I was first diagnosed I was terrified that I’d end up in a wheel chair. Now I don’t worry about that as much. MS can have my legs if it will just leave my mind alone. I hate not being able to think clearly.”

This issue of *InforMS* explores what we know about MS cognitive problems generally and from several points of view including Jeffery Gingold, who lives with cognitive problems (page 5), and neuropsychologist Dr. Brian Hoyt, who evaluates them (page 11).

COGNITIVE PROBLEMS AREN’T NEW

Charcot, who first described multiple sclerosis in medical literature 150 years ago, recognized that MS can cause memory problems and slowed thinking. Despite his findings, until about 30 years ago MS cognitive problems were widely under-recognized, misdiagnosed or simply ignored.

MS cognitive dysfunction can be hard to see with the naked eye. The problems can be quite subtle. When first experienced or observed, they are often mistaken for other MS problems such as depression or fatigue. People who have them may misattribute them to laziness, self-pity or general incompetence and be too embarrassed to disclose them. Outsiders who observe cognitive changes may attribute them to laziness, denial, bad attitude or general flakiness. Cognitive problems are also hard to identify during a brief neurology visit or in casual conversation. It is rare for someone to have severe and obvious cognitive problems that would be noticeable to most observers. Subtle impairments may get overlooked because we expect the problems to be big and obvious but generally, they aren’t.

WHAT IS COGNITION?

The human brain has been called the most complex object in the known universe. It weighs about as much as

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Cognition

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a cantaloupe—slightly less than three pounds. It contains about 100 billion neurons and enough myelinated axons (about 100,000 miles worth) to circle the equator four times. The brain is always active. It controls how we think and feel, what we learn and remember, and how we move and talk—as well as things we are less aware of, like the beating of our hearts and digestion of our breakfasts. The brain runs a tight, well-integrated ship and we aren't usually aware of how efficient it is until it stops working normally.

Cognition is a subset of brain activities. Cognition is thinking. It is all those processes that are involved in our ability to perceive, understand and navigate our world. It is comprised of different skills such as the abilities to learn, remember, organize and plan, communicate with others and make sense of what we see and experience in the world. Although in theory there are distinct categories (domains) of cognitive function, in reality, these domains don't work separately; they interact in a close, interdependent and usually seamless way to allow us to function in our environment.

Anything that changes or damages the brain can disrupt cognitive functioning. A glass of wine or an all-nighter can cause temporary changes. A closed head injury, a stroke, or a chronic condition like multiple sclerosis can cause more significant and lasting changes.

MS COGNITIVE IMPAIRMENTS

Estimates vary but probably 45 to 70 percent of people with MS experience some type of problem with their cognitive skills. Cognitive dysfunction isn't correlated with physical disability. Someone can have significant physical impairments without cognitive impairments and visa versa. Cognitive problems might be the first, or primary, or only MS symptom that someone experiences. Although it is increasingly recognized that cognitive problems can occur early in MS—even in clinically isolated syndrome (CIS)—some people have had MS for decades and do not have cognitive problems. However, according to a 2011 study, cognitive deficits are more common in people who transition from a relapsing-remitting to a secondary progressive disease course.

You have enough myelinated axons in your brain to go around the equator four times.

MS damages the brain in different ways. It demyelinates and destroys axons and can cause atrophy—that is, general shrinkage of brain tissue. The more lesions and brain atrophy you have, the more likely you are to have cognitive problems. That said, however, if you believe you are having cognitive problems, the absence of new lesions on MRI does not mean that you aren't. MRI is an imperfect tool. MRIs primarily show disease activity in the white matter; cognitive problems also result from lesions in gray matter areas of the brain that are not seen on traditional imaging.

Other factors such as depression, fatigue, sleep disturbance and medications can contribute to cognitive challenges. Improving theses problems can improve cognition. People can have increased cognitive problems during an exacerbation. For some people, these are the predominate symptoms experienced during an MS relapse, but as the relapse subsides, so do these symptoms. Although they generally progress slowly, cognitive problems that are caused primarily by the disease process in the brain often don't improve dramatically once they have begun.

Most MS cognitive problems are in the "mild" range. MS doesn't result in a global loss of cognitive abilities, like those seen in dementias such as Alzheimer's disease. However, for the person experiencing cognitive changes, "mild" can be a relative term. For most of us, "mild" suggests that a problem isn't serious. "I have a mild headache" might well be met with the internal and external reaction of, "Well, suck it up and carry on." Generally, any persistent change in our abilities to think and use our brains—even if it is "mild"—can have a significant impact on our lives. The degree of cognitive impairment may be "mild" when measured by objective standards, but the problems that result from it can be significant and impact employment, relationships and a host of other factors.

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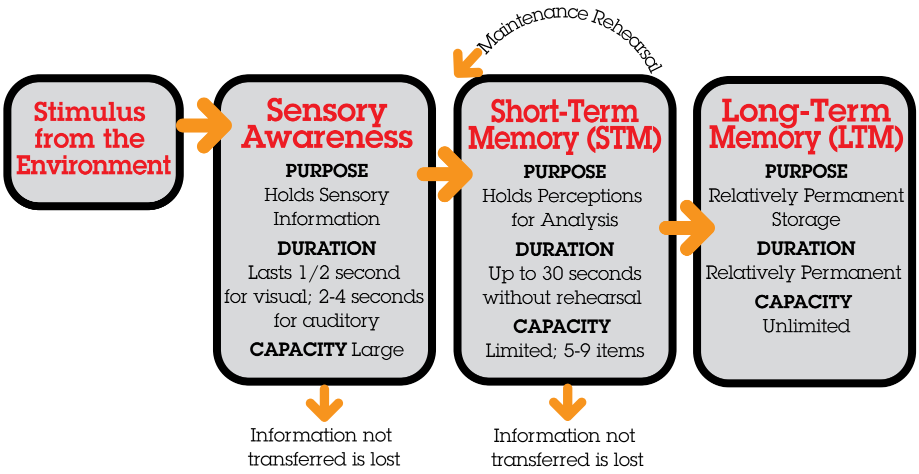

Cognition

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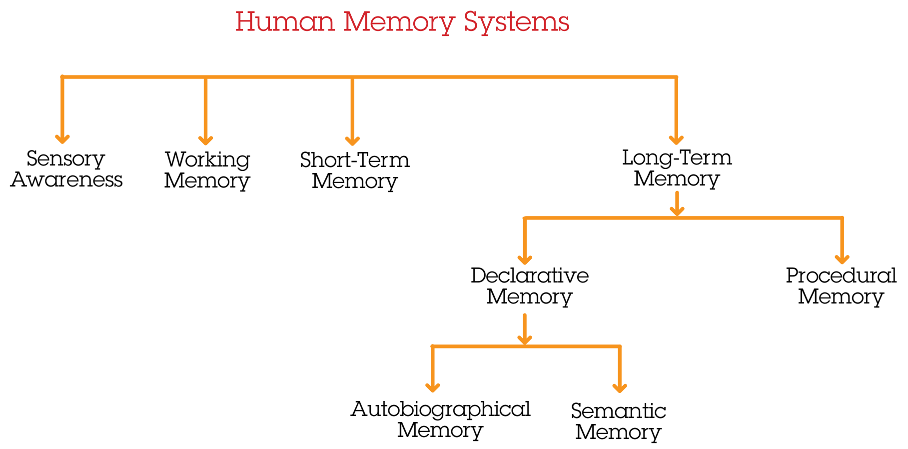


HOW DOES MS AFFECT COGNITION?

MS can affect different aspects or "domains" of cognitive functioning. The most common problems are in the areas of information processing and memory.

Information processing speed is simply how quickly you can take in and absorb the information coming at you. If your processing speed is slowed, you might have trouble digesting what you are reading or what someone is saying as quickly as you might have in the past. If multiple streams of information are hitting you at once, it might be impossible to sort them all out.

Memory, which is a very complex process, can be impaired in MS. There are different types of memory.

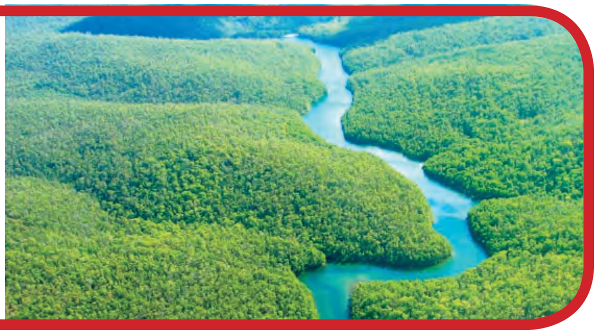
- Immediate and working memories are divisions of short-term memory. Immediate memory is the ability to keep track of and deal with whatever is happening right now. You need **immediate memory** to keep track of what you read 20 seconds ago or the important thing your spouse said to you as he was walking out the door.

- **Working memory** is the ability to hang on to information long enough to move back and forth between tasks. For example, you use your working memory to remember and get back to what you were doing before you were interrupted by a phone call.

- **Permanent, or long-term memory** is where we store what we have learned and experienced in the world. **Declarative memory** is "know what" memory about facts and events and can be consciously recalled. **Procedural memory** is "know how" memory of the well-learned skills—like riding a bicycle or driving a car—that we do almost automatically.

Immediate recall capacity and working memory are the functions most likely to be affected by MS and this can alter the ability to acquire new information and skills. Learning is really the ability to hang onto and sufficiently process the input in short-term memory so that it is transferred to long-term memory. Recent studies have found that people with MS-related memory deficits can successfully learn new information, but it may require more time and energy to do so.

Your brain contains 100 billion neurons—that's equivalent to the number of trees in the Amazon rainforest.



The ability to pay attention and concentrate on tasks can be affected by MS. It may be difficult to divide attention between competing inputs or to decide what merits the most attention and ignore the rest. It can be harder to maintain focus and filter out distractions and, for example, keep your train of thought if you are suddenly interrupted by a blaring car alarm going off outside.

Executive functioning is another cognitive domain that can be affected by MS. **Executive functioning** encompasses the ability to plan, organize and problem-solve. Problems may be generally mild but worsened by circumstances such as fatigue. Some people report that they have slightly slower problem-solving abilities than previously, especially in the afternoon if they are hot or fatigued.

People who have more severe problems with executive function may have trouble starting or completing tasks, or doing the complex reasoning that is required to make good judgments about complicated issues. Problem solving is more difficult because people don't have the cognitive flexibility that they need to generate alternative solutions. The inability to come up with alternative strategies, or the refusal to use one developed by someone else, can present as stubbornness, rigidity or denial. It may appear that someone won't change, when in fact they can't change. Insight and self-awareness can also be affected by executive function deficits, so the problems in this domain may be more apparent to other people than to the person experiencing them.

Verbal fluency is the ability to quickly

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Interview with Neuropsychologist Brian Hoyt

Teasing out the Trouble Spots

Q: Is MS brain damage?

A: It is true that MS lesions damage the brain, and over time the damage can build up and become worse so that the brain isn't working properly. But "brain damage" often has a pejorative connotation so we don't usually talk about it that way.

Q: The choice of words was deliberate. I think MS cognitive problems don't get much respect, and are often viewed as something people could get over or get around if they would just try harder They are considered more of a psychological problem than a physical problem. But it is a physical problem. The brain is damaged.

A: Yes, It is analogous to the damage we see when someone has a brain tumor or a stroke; there really is something there, and the brain is not functioning properly.

Q: How are the cognitive problems created by MS different than those you see with a stroke, or brain tumor?

A: In several ways. With MS the problems develop more slowly. People have a gradual decrease in the efficiency of cognitive functioning. Often there is a threshold where it becomes noticeable, but usually it's a gradual process. With stroke or brain tumor there is an anchoring event and a noticeable before and after change in functioning.

With MS, cognitive difficulties are often more "non-specific." People describe feeling cloudy or fuzzy or just slowed down. One of the main issues is a reduction in the speed of information processing, which in turn affects the efficiency of a person's memory functioning. When someone has a stroke in one area of the brain, it will affect one specific aspect of cognitive functioning very significantly rather than having a more diffuse effect.

Q: When do you recommend that someone get neuropsychological testing?

A: Testing is appropriate when the problems start to have enough of an effect on a person's life that it is bothersome to them. It may be affecting work performance—a supervisor is beginning to make negative comments, or they are having trouble getting tasks done. The problems may be experienced at home—there is increased bickering with family members and more general misunderstandings about things. Or maybe it's just psychologically bothersome—they feel like something is off with their thinking but they don't know what it is. Quantifying what is going on and giving people hard data to look at—whether it is good or bad—can be reassuring.

Q: When you do testing, you test people in different domains of cognitive functioning. When you find that there is a problem, can you do anything about it?

A: There are a lot of things that can disrupt cognitive functioning in people with MS in addition to the disease process. When we evaluate someone for cognitive problems, we also look at factors that have more of a secondary effect on cognition. Depression and anxiety can disrupt cognition. So can a sleep disturbance or pain or fatigue. All these things can disrupt how efficiently we cognitively.

Q: If you find that there are secondary factors and you successfully treat them, does it result in a noticeable improvement in cognitive functioning? For example, when someone is depressed and you treat that depression, it's been my experience that the person will likely feel better, but still have cognitive problems.

A: It's a matter of degrees. If someone is severely depressed and you bring that under control, you will likely see a noticeable improvement in cognitive functioning. If it is less severe you can make them feel better but that may not improve their cognition very much because it's other things that are driving the cognitive problems. The literature is variable on depression in MS and depression In general. You can find studies that detect all sorts of cognitive difficulties and you will find some that don't detect any. Especially when someone has a chronic neurologic illness, it is rare that cognitive difficulties can be attributed to depression alone. What is more likely is that depression exacerbates the cognitive difficulties that

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go along with that illness.

Q. You can treat ancillary issues, such as fatigue and depression, and get improvement in cognitive functioning. But what about things like rehabilitation or brain games? Do they change anything?

A: There really is no scientific support for brain games that are being marketed and sold to the general public. They have not been validated and there is no evidence that they actually do anything to improve cognition. The effectiveness of cognitive rehabilitation depends on the approach of the person who is providing it. The bulk of the scientific evidence supports compensations rather than remediation—utilizing strengths to minimize the effects of weaknesses. In the case of memory impairment, instead of trying to train your memory to be better, it's learning effective problem-solving, reasoning and organizational skills and implementing strategies to remind yourself of the things you are prone to forget.

Q: I've certainly read conflicting information about the usefulness of brain games and lots of criticisms that they don't improve anything except the ability to play brain games. But for the sake of argument, if you are having cognitive struggles—while I don't think that 20 minutes a day playing brain games is going to turn your life around—might it not be a place to start, in addition to doing other things?

A: As long as someone doesn't stop there or have unrealistic expectations about it "curing" them, and as long as they aren't spending a lot of money on it.

Q: The popular press and the scientific literature are full of information about brain plasticity and cognitive reserve and all the things we can and should do to keep or enhance or repair our cognitive abilities. Physical exercise is important. Intellectual exercise is important. I've read some studies that meditation improves executive functioning. What's really important?

A: We know that cognitive and physical activity have beneficial effects and that the better we take care of our physical health, the better our brains will function. How you quantify cognitive activity is all over the map. It is important to have an active and engaged intellectual life. To change your brain you can't be doing something passive, like sitting there watching TV. It has to be something that somehow engages and stimulates a new thought—stretches something. What that is for each individual is different. I am a big fan of "whatever works." If for an individual patient something enhances cognitive functioning, that's great.

> One of the main issues is a reduction in the speed of information processing, which in turn affects the efficiency of a person's memory functioning

Q: I have read some neuropsychological testing reports that say something like "patient functions in the normal range in all but this one domain." The report makes it sound like the person is mostly doing fine, with a slight problem in this one place. Yet, when you talk to the patient, it is clear that they are not doing fine. They are having all sorts of trouble, they are about to get fired, they are trying as hard as they can and they can't make it work. Why the discrepancy?

A: What you are getting at is the difference between how we identify and delineate certain cognitive functions on objective testing and what people actually experience when they live their lives and relate to the world around them. Yes, the real world effect on the person is often greater than the number of impaired domains we will notice on testing. A perfect example is someone who comes in complaining of short-term memory problems—"I can't remember what my spouse tells me to before I leave in the morning. I can't remember where I put my wallet." What we sometimes find on our testing is that a person's core memory functioning is actually intact. What they have is a problem with information processing speed. In the real world, at home, in the morning, a person may be getting ready to go to work, and their spouse is saying—"can you this, this and that today?"—and their kids are screaming in the background, and the dog is scratching at the door to go out—it's too much information coming in that needs to be processed at the same time. It's all getting processed slowly and what happens is not all of it can get in there and get processed. The information that makes it in, the person actually processes and remembers. The problem is that not all the information actually makes it in.

Q: It sounds like an equivalent situation to having car with strong engine, spotless interior, new windshield, a great sound system, and one almost flat tire. Even though 95 percent of it working fine, you can't really drive it very far.

A: Yes, with cognition, problems are usually the result of a combination of things ■.

Dr. Hoyt is the Head of the Division of Neuropsychology in the Department of Neurosurgery at the University of Colorado Hospital.

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find the words you need to express yourself and is another skill than can be impacted by MS. Word-finding problems are also a common complaint among menopausal women and the aging population in general, so complaints about these difficulties are often discounted with the comment, “That happens to me, too, and I don’t have MS.” Regardless of who else has them, these problems are frustrating, sometime embarrassing and can make it more difficult to engage in conversations.

Finally, people can have problems with **visual and spatial perception**. These problems may make it difficult to read a map, judge distances when driving, or assemble your new gas barbecue grill.

It goes without saying that the various cognitive domains do not exist in isolation, and that problems in one area can cause problems in another. For example, slowed information process may affect memory. If you can’t digest the information, you aren’t going to remember it.

SO WHAT’S THE DAMAGE?

How impaired are people by MS cognitive deficits? Studies estimate that 25 to 35 percent of people have no deficits; 40 to 50 percent of the MS population is believed to have problems in one cognitive domain; and about 20 percent may have multiple affected cognitive domains. What does this mean for someone on a day-to-day basis?

The impact on someone’s life will be influenced by factors other than the number of affected domains. Cognitive functions do not exist is just one part of the brain but are distributed networks throughout the brain. It is the ability to move rapidly all over the brain that allows us to learn and remember, so the complexity of the connections between areas of the brain also influences how we are affected by these problems.

Most of us start life with about the same number of neurons and have brains with the same basic floor plan, but how effectively and efficiently our brains work today is influenced by how we have used them in the past and are using them now. The more we use our brains, the more connections we create between neurons and the more possible routes there are from one place to another. This is known as **cognitive reserve** and is especially important if you have areas of damage and—even if your don’t—to offset the effects of normal aging. Recent studies have confirmed that people with MS who are more physically and intellectually active and have more cognitive reserve are better able to manage cognitive impairments.

Finally, how much your life is altered by cognitive problems will depend on what else is going on in your life. Cognitive problems are a frequent reason that people leave the work force. How much the problems affect your work will depend, to some extent, on what you do and which cognitive domains are

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problematic. If you have problems with working memory, you probably don't want to work as a receptionist in a busy front office where you have to keep multiple balls in the air all day long. You might, however, do just fine in the back office where fewer things are coming at you at the same time and you can control the pace and close the door.

CAN YOU FIX THEM?

"MS cognitive impairment" sounds more frightening than in most cases it actually is. For most people cognitive problems are in fact "mild" and manageable. Although we do not have sure-fire treatments that fix cognitive problems, there are things that can help you manage them.

- Take a disease-modifying drug. All of the disease-modifying therapies slow disease progression and the accumulation of new lesions on MRI. Although for the most part they don't repair the damage, they can prevent it from getting worse.
- Solve the problems you can. A lot of factors contribute to cognitive dysfunction. For example, depression may contribute seven percent; fatigue another eight, and general disorganization an additional 17 percent. Fixing these problems won't turn your life around, but it could get you a modest 30 percent improvement.
- Get an evaluation. Neuropsychologists, specialized speech and language pathologists, and specialized occupational therapists all evaluate cognitive problems, albeit in different ways. Finding out what your strengths and weaknesses are can help you begin to develop strategies that strengthen the former and work around the latter.
- Exercise your body and brain. Physical exercise is important. Intellectual stimulation is important, too. Not all things work for all people. The best exercise regimens are the ones that you will actually do regularly. For more information on cognitive reserve, and exercise, please see *InforMS* Summer 2010, available online at http://bit.ly/16PqK6G.
- Specialized speech language and occupational therapists are both trained to help people develop compensatory strategies tailored to their individual situation and needs.
- Some medications might be helpful. Drugs that treat fatigue are helpful for some people. Ampyra, a drug that speeds nerve condition and is used primarily to improve walking, is sometime helpful for cognitive problems.

The human brain is the most complex thing in the known universe. Human beings are pretty complicated, too. The capacity of both our brains and our beings to grow, change, adapt and adjust is almost limitless.

Most people who have MS cognitive problems find them initially unnerving and, as time goes on, perpetually annoying but for the most part, they manage—with practice, patience, help and time—to accommodate them. ■

Meet Nancy Davis

Join us Saturday, October 26th, 2013 at the Infinity Event Center in Glendale, Colorado to congratulate Nancy Davis on 20 years of success and her passionate work to advance the search for a cure for MS. We are honored to bring this extraordinary woman back to her native Colorado, along with her enthusiasm and expertise.

Born and raised in Denver, the daughter of Barbara Davis and the late Marvin Davis, Nancy was diagnosed with MS in 1991 at the age of 34. After being told by her doctors that she would be "lucky" to operate the remote control on her TV, she realized she was too young and too busy to let the disease stop her life in its tracks. She was determined to devote her time, relationships and resources to finding a cure. Nancy's hope, courage and strength continue to inspire her to maintain a vibrant quality of life despite this chronic disease. She remains positive, continues to live her life to the fullest and is tireless in her efforts to find a cure for MS.

In 1993 Nancy founded the Race to Erase MS – an organization focused on advancing the most promising, cutting-edge research to find a cure for MS. Nancy is also the founder of the "Nancy Davis Center Without Walls" program. The Center is a network of top-tier MS institutions with leading, innovative research programs that work as a team, constantly communicating, never duplicating. This nationwide collaborative of physicians, scientists and clinicians continuously develops research programs and therapeutic approaches to eradicate MS by linking multidisciplinary scientific programs and experts across the country.

Visit www.makingmshistory.org for event information. ■

Nancy Davis with Sharon, Jack, and Kelly Osbourne. In June 2012, Jack Osbourne announced that he had been diagnosed with MS.

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HONORING NANCY DAVIS

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CALENDAR

Every Month

MS 101 Empowerment through education for the newly diagnosed. Join Pat Daily, LCSW, for an informal discussion of issues important to people newly diagnosed with MS. Family members and friends are welcome. There is no charge, but registration is required and class size is limited. Call 303-788-4030 x 120 to learn more. **Aurora, Denver and Westminster, CO**

August

Monday, 26th **N. Darin Writer Memorial Golf Tournament,** Pinehurst Country Club. Sponsorships Available: Call 303-788-4030 ext. 111 Fees include lunch, awards reception dinner and opportunity to play one of the best CO courses. **Denver, CO**

September

Saturday, 7th **Gadgets, Gizmos & Strategies – Making Life Easier with MS** Mark your calendar! More information to come. MS Center, **Westminster, CO**

Monday, 9th **MS 101** See description above. **Denver, CO**

Tuesday, 17th **Q&A with Dr. Vollmer** See description above. **Greeley, CO**

Friday, 20th **MS 101** See description above. **Aurora, CO**

Saturday, 21st **Legal Issues and MS: Employment, Disability, Health Directives** This seminar will feature nationally recognized speakers as they discuss MS and your legal rights. **Westminster, CO**

October

Monday, 7th **MS 101** See description above. **Denver, CO**

Saturday, 12th **Invisible Symptoms of MS – Cognition, Depression & Fatigue,** Dr. Vollmer, Pat Daily, Jeffrey Gingold. Learn about the clinical approaches to treating these challenging, misunderstood, discounted, and invisible symptoms. Denver West Marriott, **Golden, CO.**

Saturday, 26th **MS Center Annual Gala Celebrates Hollywood** Infinity Event Center, **Glendale, CO.** www.makingmshistory.org

Monday, 28th **MS 101** See description above. **Westminster, CO**

Q&A with Dr. Vollmer Visit with Dr. Tim Vollmer, the Medical Director of the MS Center, and get your questions answered. Audience participation is encouraged. To learn more or register, visit www.mscenter.org and click on news and events.

September 17th **Greeley, CO**
October 25th **Glenwood Springs, CO**

November

Friday, 15th **MS 101** See description above. **Aurora, CO**

Saturday, 16th **Scientific Advances in MS Research and Treatments,** Tim Vollmer, John Corboy, Enrique Alvarez, Teri Schreiner. Learn the breaking news in MS. This seminar will offer a special breakout session on Pediatric MS and an opportunity to meet the newest addition to the MS Center at AMC Clinic – Dr. Enrique Alvarez. Summit Event Center, **Aurora, CO**

Monday, 25th **MS 101** See description above. **Westminster, CO**