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Winter/Spring 2015

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COVER STORY

Cognitive Issues with MS: Research, Strategies, and Support

By Susan Wells Courtney 3

Study results and treatment strategies for this challenging symptom are presented.

DEPARTMENTS

Up Front By Douglas G. Franklin 2
MSSA's president and CEO talks about MSSA's new headquarters.

Ask the Doctor By Jack Burks, MD 34
MSSA's chief medical officer answers questions sent in by readers.

Research News By Susan Wells Courtney 37
Important research findings and approvals from the past six months are featured.

Program Notes By Peter Damiri 42
MSSA's MRI Access Fund, summer cooling accessories, and online-video milestone are highlighted.

Thoughts about Giving By Kimberly Goodrich 44
This issue's column talks about the importance of leaving a legacy to the MS community.

Stories to Inspire By Tina Torizzo 46
Tina talks about how Crane, her service dog, has improved her quality of life and safety.

Spread the Word 48
Three books from MSSA's free Lending Library are featured.

Please send comments regarding *The Motivator* to editor@mymsaa.org



Improving Lives Today!

The Multiple Sclerosis Association of America is a leading resource for the entire MS community, improving lives today through vital services and support.



MSSA strives to provide useful, up-to-date information on matters of concern to MS patients and their families. This material is intended for general informational purposes only, and it does not constitute medical advice. You should not use the information presented as a means of diagnosis or for determining treatment. For diagnosis and treatment options, you are urged to consult your physician.

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A portion of this magazine has been printed on recycled paper using soy-based ink.



Douglas G. Franklin

MSAA's New Home

Many of us have been hit hard this winter with particularly cold weather and lots of snow – including Boston at 103-plus inches – but as they say in the literature, “hope springs eternal.” With this spring season upon us, we are all looking forward to longer days of sunlight and milder weather... along with other annual activities... such as spring cleaning! For MSAA, spring cleaning has taken on new meaning, as our headquarters is moving to a new location here in Cherry Hill, New Jersey.

Our new building is approximately two miles from our current location. This new office space is undergoing renovations and upgrading, which will allow for programmatic expansion in the future. Our current building has served us well since MSAA bought it in 1995, but this is now an opportune time to sell, given all of the new commercial development around us. MSAA's new premises will be a good fit for our national headquarters as we move to a quieter street and make a profit on the transaction in the process.

In addition, the size and layout of our new headquarters will allow for greater improvements in our computer systems and other technology. Any improvements in these areas will enable us to serve the MS community even more efficiently, and this is exciting news. We expect to make our move in June and the new MSAA address will be:

**375 Kings Highway North
Cherry Hill, New Jersey 08034**

Our phone number, email, and website address will all remain the same. Together, we will continue our efforts of Improving Lives Today! In closing, I want to thank all of our supporters and friends across the country who continue to help us help others. Together we are making good things happen! ♦

Doug Franklin joined MSAA as President & CEO in 1999. He has a distinguished career in nonprofit leadership and is a former national trainer in strategic planning for the Peter Drucker Foundation. A published international expert in social marketing and corporate social investment, he is a graduate of four universities and holds dual certifications in two professional associations. He currently serves on the National Board of the Key Philanthropic Organizations Committee of the American Society of Association Executives and as President of the Multiple Sclerosis Coalition.



Cognitive Issues

with
Multiple
Sclerosis

RESEARCH, STRATEGIES, AND SUPPORT

By Susan Wells Courtney

Reviewed by Jack Burks, MD

Cognitive changes with multiple sclerosis (MS) are fairly common. Most studies state that approximately 50 percent of individuals with MS may have some type of cognitive dysfunction, although some estimates are as high as 60 or even 70 percent. Individuals with MS who experience cognitive issues may have trouble with functions such as attention, information-processing speed, executive functions (decision making), episodic memory, and visuospatial abilities. These deficits can affect several activities of daily living, including employment, driving, social integration, and adherence to medication regimens. Concentration and attention shifting are other examples of cognition impairments observed with MS.

The study of cognitive changes with MS is both extensive and varied, yet still in its early stages. A search of peer-reviewed articles reveals findings from hundreds of recent trials within the past few years, conducted in countries all over the world, and covering a wide range of objectives – from evaluating assessment tools and looking at cognition’s impact on quality of life, to identifying

potential causes and determining the effectiveness of certain treatment strategies.

Why is the study of cognition in MS so complex? This is because so many variables exist with this symptom and its manifestations. For example, cognitive changes can be a difficult area to measure and to compare with controls. Researchers are looking for the optimal tests to best evaluate the presence, type, and severity of cognitive deficits in different individuals with MS. The variety of tests used in these trials is impressive; for example, these may include questionnaires, dual-task evaluations, measures of eye movements, computerized tests of cognitive function, an array of physical, mental, and emotional scales, several types of neuroimaging, and more.

Even with all of these tools, many questions still remain. For instance, when an individual with cognitive issues provides self-reported evaluations, are these answers valid? The findings from a study in France suggest that cognitive dysfunction did not compromise the reliability or validity of one’s responses on quality of life questionnaires, but these types of issues need to be considered when conducting studies on the effects of cognitive problems.

Further complicating this issue is the fact that medications used for symptom management may also affect cognition as a side effect, and this too must be included in the equation.

Neuroimaging is vital in determining what specific areas of the brain may be affected by MS to cause cognitive problems, as well as parts of the brain that may compensate for areas that are no longer conducting nerve impulses efficiently. Many forms of imaging technology are used for this purpose and can provide important data to researchers, enabling them to theorize the different areas of the brain that may impact cognition. Some of these types of tests are used to observe the activity in parts of the brain while a patient performs a task, and these data may be compared to someone without cognitive issues performing the same task.

Additionally, the type or stage of MS can exhibit different types and degrees of cognitive changes. Researchers are studying both relapsing and progressive forms of MS, as well as individuals with clinically isolated syndrome (CIS) and pediatric MS. Studies are also being conducted to determine if other symptoms may impact cognition, such as depression and other changes in mood, fatigue, poor sleep, and more. And perhaps the biggest variable in evaluating cognitive issues in MS is the day-to-day variations in symptoms as well as during times of exacerbations or pseudo-exacerbations.

Demographics are another area of interest, and in this category, gender may even play a role. A Spanish study found that gender may have an impact on cognitive performance, and in this instance, found that males with MS exhibited poorer cognitive performance,

largely in terms of verbal auditory memory. However, a study in Finland found that male patients with severe attentional deficits benefited more from neuropsychological intervention, as compared to females in the study. Much remains to be learned about this challenging symptom, and as illustrated in this example, a variety of outcomes may be derived from this research.

As researchers delve further into the effects of cognitive issues in MS and look to find the causes, another important area of study is that which evaluates the effectiveness of potential treatments. Different forms of exercise as well as various types of cognitive training/ neuropsychological rehabilitation are two areas of potential treatments that are being studied closely.

Many trials are also underway to look at the effectiveness of the different approved and experimental disease-modifying therapies in delaying, improving, or preventing cognitive symptoms. Other treatments, such as fampridine, statins, and vitamin A, are now including changes in cognition among their study endpoints.

The many variables mentioned above are just examples of the great complexity involved with learning about and treating cognitive dysfunction in MS. In the pages to follow, this article will provide excerpts from published studies from around the world, aimed at evaluating this challenging symptom and its potential causes, along with various treatment strategies. Readers may also learn about current studies and hear from two professionals who work closely with individuals experiencing cognitive issues from MS.

DESCRIBING COGNITIVE DYSFUNCTION

Acclaimed author Jeffrey N. Gingold, writer of *Facing the Cognitive Challenges of Multiple Sclerosis, Second Edition* (Demos Health, 2011) and *Mental Sharpening Stones* (Demos Health, 2008), has been able to put into words exactly what it feels like to experience a sudden lapse in cognition, where familiar surroundings are no longer familiar, and well-versed words cannot be found.

In *Facing the Cognitive Challenges of Multiple Sclerosis, Second Edition*, Mr. Gingold talks about his work as a successful lawyer who is suddenly faced with a host of cognitive challenges, some of which arise at the most inopportune of times. At right are excerpts from the Preface of this book, touching briefly on his experience with cognitive issues from MS.

Another book written by Mr. Gingold, *Mental Sharpening Stones*, also provides detailed descriptions of sudden lapses in cognition. It goes on to give valuable direction and tips for managing this symptom. Other books are available on the topic of cognition and MS, including *Multiple Sclerosis: Understanding the Cognitive Challenges*, which is an excellent resource written by Nicholas LaRocca, PhD and Rosalind Kalb, PhD (Demos Medical Publishing, 2006). All three of these books, as well as others, may be borrowed at no charge from MSAA's Lending Library. Please see page 48 for details about this helpful program.

“How would you handle getting lost while driving home – only blocks from your house? Would you be able and willing to explain it to your doctor? To your friends and family? Your spouse? When I was first diagnosed with multiple sclerosis (MS) in 1996, I envisioned being physically disabled, relegated to spending family time and a successful legal career in a permanently seated position. I never anticipated that MS would also include an invisible disability, a ‘mental wheelchair’ that would confound my recollection and distort my rational presence of mind, turning court appearances and the routine moments of life into mental quicksand.”

“Without warning, many people with MS are suddenly faced with an inability to process routine thoughts. Their decision making may be stonewalled, befuddling simple conversations into a word-finding struggle. Others may lose their bearings in their own backyard or kitchen, or suddenly the face of a spouse or friend will appear unfamiliar. Then, the shroud over their memory recall lifts, defying explanation, and leaving no trace of the bait and switch. The individual’s cognitive functions have been compromised and often go undiagnosed, creating a deep chasm of unseen disability.”

**– Jeffrey N. Gingold,
*Facing the Cognitive Challenges of
Multiple Sclerosis, Second Edition***

EXPERIENCE

COPAXONE® (glatiramer acetate injection) is indicated for the treatment of patients with relapsing forms of multiple sclerosis.

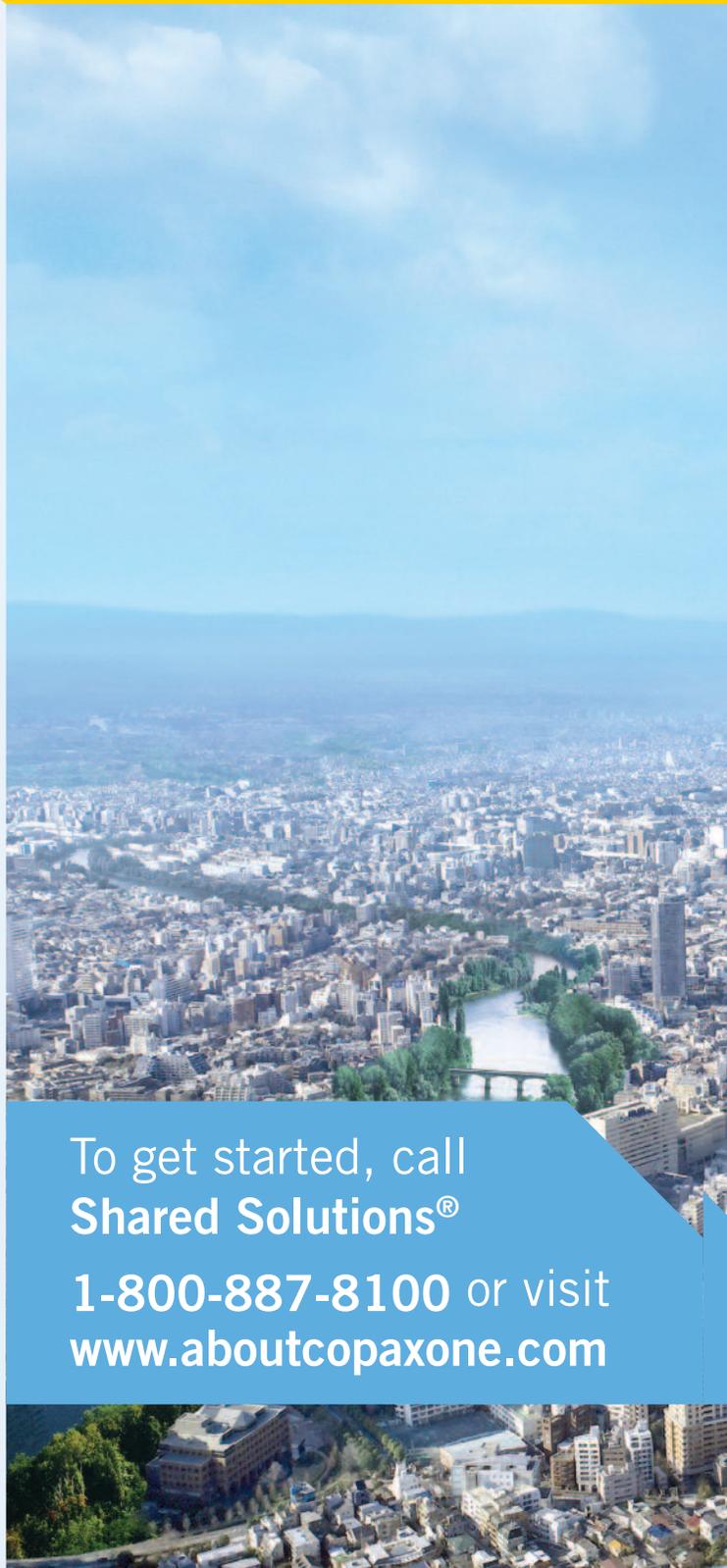
Important Safety Information

Do not take COPAXONE® if you are allergic to glatiramer acetate or mannitol.

Some patients report a short-term reaction right after injecting COPAXONE®. This reaction can involve flushing (feeling of warmth and/or redness), chest tightness or pain with heart palpitations, anxiety, and trouble breathing. These symptoms generally appear within minutes of an injection, last about 15 minutes, and do not require specific treatment. During the postmarketing period, there have been reports of patients with similar symptoms who received emergency medical care.

If symptoms become severe, call the emergency phone number in your area.

Please see additional Important Safety Information and brief summary of full Prescribing Information on the following pages.



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www.aboutcopaxone.com

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Important Safety Information (cont'd)

Call your doctor right away if you develop hives, skin rash with irritation, dizziness, sweating, chest pain, trouble breathing, or severe pain at the injection site. If any of the above occurs, do not give yourself any more injections until your doctor tells you to begin again.

Chest pain may occur either as part of the immediate postinjection reaction or on its own. This pain should only last a few minutes. You may experience more than one such episode, usually beginning at least one month after starting treatment. Tell your doctor if you experience chest pain that lasts for a long time or feels very intense.

A permanent indentation under the skin (lipoatrophy or, rarely, necrosis) at the injection site may occur, due to local destruction of fat tissue. Be sure to follow proper injection technique and inform your doctor of any skin changes.

The most common side effects in studies of COPAXONE® (glatiramer acetate injection) are redness, pain, swelling, itching, or a lump at the site of injection, flushing, rash, shortness of breath, and chest pain. These are not all of the possible side effects of COPAXONE®. For a complete list, ask your doctor or pharmacist. Tell your doctor about any side effects you have while taking COPAXONE®.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

Please see brief summary of full Prescribing Information on the following page.

Patient Information

COPAXONE (co-PAX-own) (glatiramer acetate injection) for subcutaneous use

Read this Patient Information before you start using COPAXONE and each time you get a refill. There may be new information. This information does not take the place of talking with your doctor about your medical condition or your treatment.

What is COPAXONE?

COPAXONE is prescription medicine used for the treatment of people with relapsing forms of multiple sclerosis (MS). It is not known if COPAXONE is safe and effective in children under 18 years of age.

Who should not use COPAXONE?

- Do not use COPAXONE if you are allergic to glatiramer acetate, mannitol or any of the ingredients in COPAXONE. See the end of this leaflet for a complete list of the ingredients in COPAXONE.

What should I tell my doctor before using COPAXONE?

Before you use COPAXONE, tell your doctor if you:

- are pregnant or plan to become pregnant. It is not known if COPAXONE will harm your unborn baby.
- are breastfeeding or plan to breastfeed. It is not known if COPAXONE passes into your breast milk. Talk to your doctor about the best way to feed your baby while using COPAXONE.

Tell your doctor about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. COPAXONE may affect the way other medicines work, and other medicines may affect how COPAXONE works.

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

How should I use COPAXONE?

- For detailed instructions, see the **Full Prescribing Information** for complete information on how to use COPAXONE.
- Your doctor will tell you how much COPAXONE to use and when to use it.
- COPAXONE is given by injection under your skin (subcutaneously).
- Use COPAXONE exactly as your doctor tells you to use it.
- Since every body type is different, talk with your doctor about the injection areas that are best for you.
- You should receive your first dose of COPAXONE with a doctor or nurse present. This might be at your doctor's office or with a visiting home health nurse who will teach you how to give your COPAXONE injections.

What are the possible side effects of COPAXONE?

COPAXONE may cause serious side effects, including:

- **Post-Injection Reactions.** Serious side effects may happen right after you inject COPAXONE at any time during your course of treatment. Call your doctor right away if you have any of these post-injection reaction symptoms including:
 - redness to your cheeks or other parts of the body (flushing)
 - chest pain
 - fast heart beat
 - anxiety
 - breathing problems or tightness in your throat
 - swelling, rash, hives, or itchingIf you have symptoms of a post-injection reaction, do not give yourself more injections until a doctor tells you to.
- **Chest Pain.** You can have chest pain as part of a post-injection reaction or by itself. This type of chest pain usually lasts a few minutes and can begin around 1 month after you start using COPAXONE. Call your doctor right away if you have chest pain while using COPAXONE.

- **Damage to your skin.** Damage to the fatty tissue just under your skin's surface (lipoatrophy) and, rarely, death of your skin tissue (necrosis) can happen when you use COPAXONE. Damage to the fatty tissue under your skin can cause a "dent" at the injection site that may not go away. You can reduce your chance of developing these problems by:
 - following your doctor's instructions for how to use COPAXONE
 - choosing a different injection area each time you use COPAXONE. **See Step 4 in the Instructions for Use, "Choose your injection area".**

The most common side effects of COPAXONE include:

- skin problems at your injection site including:
 - redness
 - pain
 - swelling
 - itching
 - lumps
 - rash
 - shortness of breath
 - flushing (vasodilation)
- 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 COPAXONE. For more information, ask your doctor or pharmacist.

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

How should I store COPAXONE?

- Store COPAXONE in the refrigerator between 36°F to 46°F (2°C to 8°C).
- When you are not able to refrigerate COPAXONE, you may store it for up to 1 month at room temperature between 59°F to 86°F (15°C to 30°C).
- Protect COPAXONE from light or high temperature.
- Do not freeze COPAXONE syringes. If a syringe freezes, throw it away in a sharps disposal container. **See Step 13 in the Instructions for Use, "Dispose of needles and syringes".**

Keep COPAXONE and all medicines out of the reach of children.

General information about the safe and effective use of COPAXONE.

Medicines are sometimes prescribed for purposes other than those listed in a Patient Information Leaflet. Do not use COPAXONE for a condition for which it was not prescribed. Do not give COPAXONE to other people, even if they have the same symptoms as you have. It may harm them.

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

For more information, go to www.copaxone.com or call 1-800-887-8100.

What are the ingredients in COPAXONE?

Active ingredient: glatiramer acetate

Inactive ingredients: mannitol



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This brief summary is based on COPAXONE FDA-approved patient labeling, revised: January 2014.

COP-41059

CAUSES OF COGNITIVE SYMPTOMS

Descriptions and Makeup of the Brain

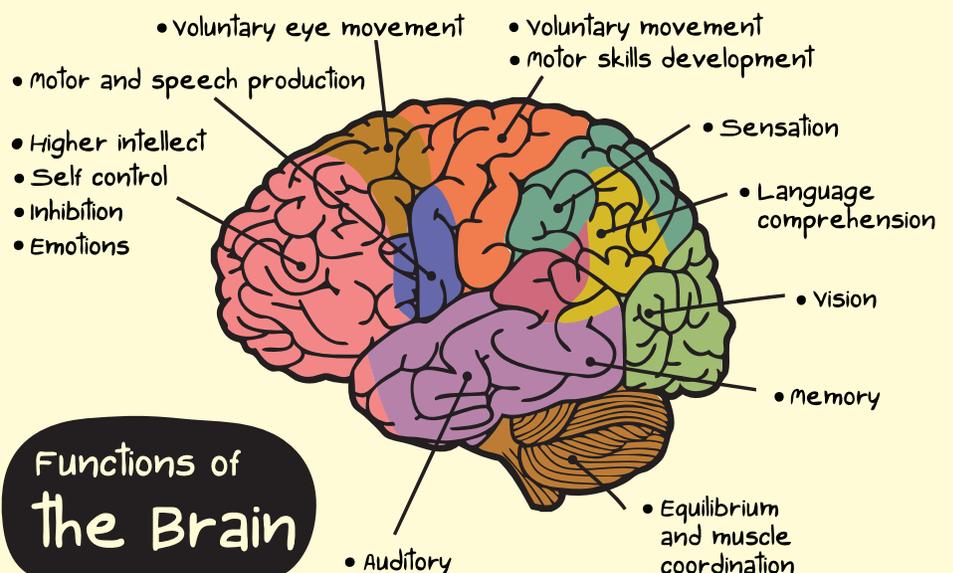
What leads to cognitive problems in MS? Changes in the brain caused by damage to the myelin and axons (nerves in the brain) are the primary cause of cognitive dysfunction in MS. Research is ongoing to identify the exact locations of damage that cause cognition issues in individuals with MS. Additionally, damage to different locations of the brain affect different types of cognitive function, such as attention, information-processing speed, executive function, and memory, to name a few. The hope is that through such studies, treatments may eventually be designed to target these areas and minimize or prevent any effects that MS may have on cognition.

The term “cognition” refers to a group of mental processes such as information processing, language, memory, visual perception/spatial skills, calculation skills, and executive functions (LaRocca, Sorenson and Fischer, 2000). These may be described as follows:

- Information-processing skills affect our ability to focus, maintain, and shift our attention from one thing to another without losing track of what we were doing, as well as managing incoming information quickly.
- Language refers to the ability to understand and use language appropriately in daily situations.

- Memory is a complex set of skills that involve learning, storage of information, and the ability to retrieve that information on demand.
- Visual perceptual/spatial skills allow us to do things such as recognize objects, draw, assemble things, and find our way around.
- Performing simple and complex math skills are involved in calculation abilities.
- Executive-functioning abilities enable us to get through our day by overseeing and coordinating tasks such as organization, planning, sequencing, problem solving, judgment, reasoning, monitoring our own behavior, etc.

The most commonly affected cognitive processes in MS are speed-of-information processing, memory, and executive functions. Other domains of cognition can also be affected depending on where lesions are located. However, rarely are all domains of cognition impacted by MS.



Glossary of Terms

Basal ganglia and thalamus

These are structures at the base of the brain composed of nerve cells; they are responsible for body movements and coordination. They also function as a relay center for sensory impulses to the cerebral cortex. Damage in this area may cause cognitive problems.

Brain atrophy

A wasting or decrease in size of part of the brain because of disease, such as MS.

Brainstem (midbrain, pons, and medulla)

Brain structure connecting the cerebrum pathways to the spinal cord, which leads to nerves in the arms and legs. It also controls vital functions, movement, sensation, and nerves supplying the head and neck.

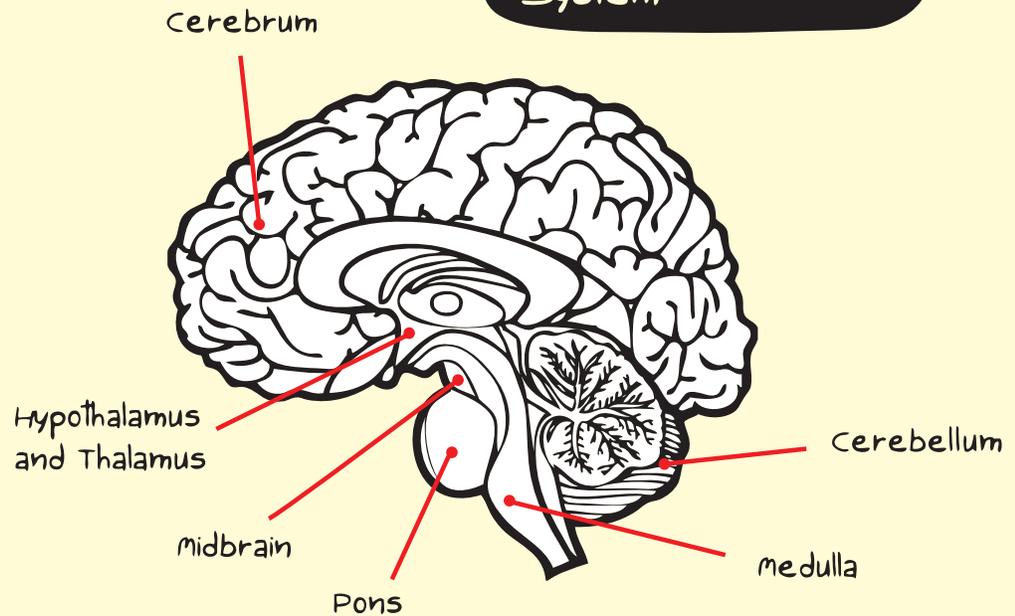
Cerebellum

The cerebellum is at the base and the back of the brain. The cerebellum is responsible for coordination and balance.

Cerebral cortex/gray matter

This is the outer gray matter of the cerebrum, where many of the higher functions, such as volition, consciousness, conceptualization, motor activity, speech, and sensation, are carried out. This gray matter is mainly composed of nerve cells.

Central Nervous System



Cerebrum

This is the large, top portion of the brain that is divided into four lobes and is joined at the bottom by the corpus callosum. It controls and integrates motor, sensory, and higher mental functions, such as thought, reason, emotion, and memory.

The four sections of lobes that make up the cerebrum are:

- The frontal lobes that are responsible for problem solving, judgment, and motor function.
- The parietal lobes that manage sensation, handwriting, and body position.
- The temporal lobes, including the hippocampus and limbic system, are involved with memory and hearing.

- The occipital lobes that contain the brain's visual processing system.

Corpus callosum

Part of the cerebrum, this is a plate of nerve fibers connecting the two cerebral hemispheres, except for most of the temporal lobes.

White matter

Areas of the nervous system composed mostly of myelinated nerve fibers (those having myelin sheaths) that conduct nerve impulses.

Changes in the Brain That May Lead to Cognitive Problems

Please note that portions of the information appearing in this article are described in “Cognition, Cognitive Dysfunction, and Cognitive Rehabilitation in Multiple Sclerosis,” written by Pepping M, et al, Phys Med Rehabil Clin N Am 24 (2013) 663-672.

Both acute inflammatory demyelination and axonal degeneration are thought to be the primary causes of MS-related disability. Although MS is often considered to be a disorder affecting only subcortical white matter, considerable evidence has shown that cortical demyelination can also occur, even at early stages of disease. Since both subcortical and cortical brain regions appear to be affected, this indicates that the nature of MS is diffuse (spread over a wide area), and may explain why a widespread set of cognitive issues are possible.

What is notable about this data is the fact that MS damage leading to disability was at

one time thought to be limited to white matter. The axons (nerves in the brain) found in white matter are insulated by myelin, which is the primary target of MS damage. However, when MS damage extends to the gray matter – consisting of dense nerve cells and myelin that is less apparent – additional disability, including cognition, can be affected. Gray matter damage is usually more widespread than the more well-defined white-matter lesions. This is why damage going beyond the white matter and extending into the gray matter is often referred to as “diffuse.”

According to the authors of this article, despite the potential for diffuse brain involvement, MS lesions tend to locate in white matter, the cerebellum, and the brainstem. White-matter lesion load (or burden), the location of the lesions, and the amount of global or regional brain atrophy – which is the shrinking or reduction in brain volume – are of greatest interest in the study of cognitive dysfunction in MS. To follow are some examples of MS damage and the type of cognitive functions that they affect:

- Lesion load in areas near the cortex may cause problems with memory
- MS damage in the frontal lobe can affect executive function (which includes judgement and problem solving)
- Global and regional brain atrophy is particularly associated with cognitive dysfunction

Additionally, in some studies, brain atrophy (reduction in tissue) was found to contribute more to cognitive impairment than the degree



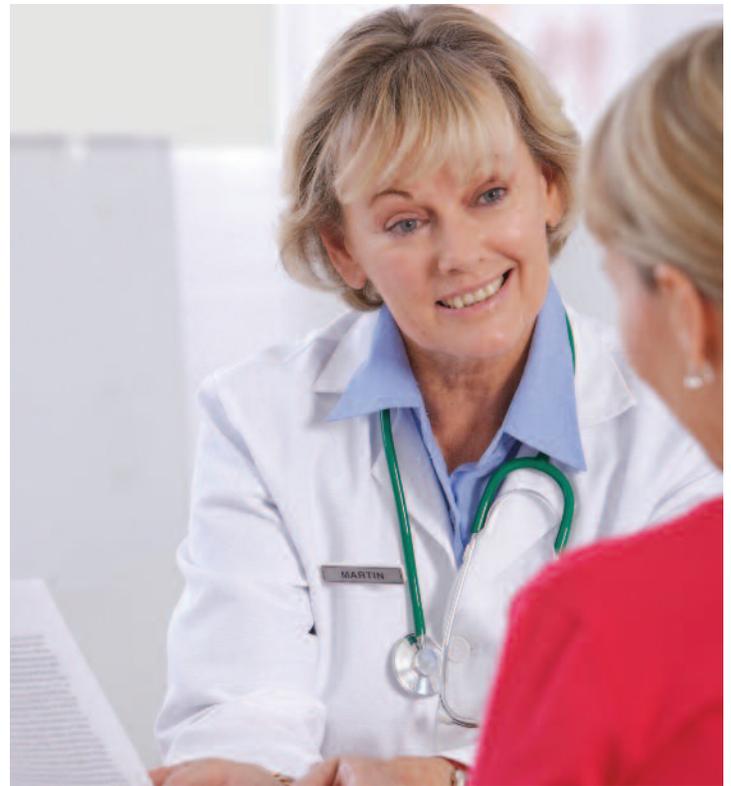
of lesion load. Other examples of damage that appear to affect cognitive function include:

- The width of the third ventricle, which was more highly associated with cognitive dysfunction than whole-brain (overall) atrophy
- A central role of the thalamus is to act as a relay station for the transmission of information between different areas of the brain; this could explain why atrophy in these areas has significant effects on key frontal-subcortical functions, which include thought and memory
- In some studies, cognitive impairment and atrophy of the thalamus were particularly linked to men – although the reason for this is not known

To follow are a few brief findings from recent studies, which suggest that different areas of the brain may play a role in cognitive symptoms with MS. As readers can see, researchers have differing opinions as to what areas or factors have the greatest impact on cognitive functioning. These reports are just a sampling of the many studies that have been published within the past few years.

A study from Buffalo, New York states that there is a well-established correlation between **deep gray matter atrophy** and cognitive dysfunction in MS. The study's findings also suggest that **iron accumulation in the thalamus** may play a role in MS cognitive decline.

An international study reports that changes in the **basal ganglia, such as the thalamas**, are related to mobility and cognitive impairment.



A study from Cleveland, Ohio indicates that in patients with MS, hippocampal volume (the hippocampus is part of the temporal lobe in the cerebral cortex) was related to reduced memory and information-processing speed. These results highlight the role of the **hippocampus** in cognitive dysfunction in patients with MS and suggest that measures of hippocampal atrophy could be used to capture aspects of disease progression.

A study in Switzerland indicates that **cerebellar abnormalities** can contribute to disability, including cognitive impairment in MS.

Researchers in the United Kingdom linked **Glutamate**, an excitatory neurotransmitter, with memory problems.

Researchers in Canada report that they investigated the association between cognitive impairment and **white matter** dysfunction in secondary-progressive multiple sclerosis.

Other Factors that May Play a Role in Cognitive Problems in MS

Other factors may be involved with the cognitive symptoms of MS. To follow is a listing of some of these factors that have been hypothesized or implicated in recent studies.

Isolated Cognitive Relapses: From a study conducted in several countries, “While cognition can be affected during sensorimotor multiple sclerosis (MS) relapses, the relevance of isolated cognitive relapses (ICRs, i.e., those occurring in absence of new sensorimotor symptoms) remain poorly characterized. Here, we decided to explore the relationship between ICR, subjective evaluation of cognitive performance and long-term cognitive decline in a group of subjects with relapsing-remitting MS... Subjects who presented with an ICR [at six months into the study] presented with a

significantly reduced cognitive performance at the follow-up evaluations compared with patients without ICR.”

Polypharmacy (use of multiple medications): Researchers in Kansas City reported that patients with multiple sclerosis (MS) commonly use a variety of medications to slow disease progression, alleviate symptoms, and treat comorbid conditions. The use of multiple medications (polypharmacy) can be associated with additional fatigue and memory problems. The investigators recommend that patients and healthcare professionals weigh the risks and the benefits of using multiple medications at one time, given the potential for a possible increase in fatigue and cognitive issues.

Smoking: Investigators in Istanbul, Turkey explain, “According to the results of our study, heavy smokers had increased cognitive impairment when compared to nonsmokers. Extensive studies are necessary to further elucidate the relationship between smoking and cognitive impairment in MS patients.”

Gut microbiota: Italian researchers suggest that the potential relationship with bacteria in the GI tracts and their potential influence on the immune system in neurological disease (such as MS), with an impact on pain and cognition. Mutual impact of gastrointestinal tract (GIT) and central nervous system (CNS) functions has been recognized since the mid-twentieth century. They studied how the commensal gut microbiota influences systemic immune response in some neurological disorders, highlighting its impact on pain and cognition in multiple sclerosis.



ADDITIONAL RECENT STUDY FINDINGS

To follow are some recently reported study findings, helping to provide a broader understanding of the impact and variables in cognitive dysfunction as a symptom of MS, as well as help to identify the most useful methods of assessment.

Assessment Tools

A German study explains, “Patients with relapsing-remitting multiple sclerosis and age- and gender-matched healthy individuals were tested with common neuropsychological tests and a **computer-based visual search task**, whereby a target stimulus has to be detected amongst distracting stimuli on a touch screen... [The researchers concluded that] visual search is a promising instrument for the assessment of cognitive functions and potentially cognitive changes in patients with multiple sclerosis thanks to its good discriminatory power and insusceptibility to practice effects.”

In Kansas City, Missouri, researchers explain, “Eye movement difficulties in multiple sclerosis (MS) are common and may influence performance on cognitive tests... [Two] studies examined associations between a new measure of **speedy eye movement** and visual/nonvisual cognitive tests. In both studies, slower eye movements were significantly associated with poorer performance on cognitive tests... Pending further research, the Speedy Eyes Test [SET], a brief, inexpensive, and nontechnical measure of speedy eye movement, may serve as a visual/oculomotor indicator of cognitive impairment in multiple sclerosis.”

Dual Tasks of Walking and Cognition

The University of Illinois report that performing a cognitive task, while walking, results in a reduction of walking performance among persons with MS. Any loss in function that occurs because of doing two tasks at one time is referred to as dual-task cost, or DTC.

Study investigators examined walking performance, cognitive processing speed, and symptoms of fatigue, depression, anxiety, and pain as correlates of DTC of walking in MS. There were significant and large declines in gait performance with the addition of a cognitive task for velocity, cadence, and step length. Walking performance might be a target of interventions for reducing the DTC of walking in MS.

Cognitive rehabilitation (discussed later) encourages people with cognitive issues to stay active and employ helpful strategies. These strategies include planning ahead and using written notes – both for memory prompts and for increased organization.



For adults
with MS-related
walking
difficulties



THE 7:16 WAS ON TIME
BUT MY LEGS WERE
BEHIND SCHEDULE

Actor portrayal

AMPYRA® (dalfampridine) Extended Release Tablets, 10 mg, is the only product indicated to improve walking in patients with MS. This was demonstrated by an increase in walking speed.

AMPYRA does not work for everyone, and people experience different levels of response to the medication. Ask your doctor if AMPYRA may be right for you.

IMPORTANT SAFETY INFORMATION

Do not take AMPYRA if you

- have ever had a seizure,
- have certain types of kidney problems, or
- are allergic to dalfampridine (4-aminopyridine), the active ingredient in AMPYRA.

Take AMPYRA exactly as prescribed by your doctor.

Before taking AMPYRA, tell your doctor if you

- have kidney problems or any other medical conditions
- are taking compounded 4-aminopyridine
- are pregnant or plan to become pregnant. It is not known if AMPYRA will harm your unborn baby.
- 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.
- are taking any other medicines

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

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 before you start AMPYRA.



ampyra®

(dalfampridine) 10 mg
EXTENDED RELEASE TABLETS

THAT'S WHEN I ASKED FOR THE WALKING PILL

Today is the day to ask your doctor about a **FREE* 60-day trial**. Find out more at AmpyraFreeTrial.com

*Limitations and restrictions apply.

IMPORTANT SAFETY INFORMATION continued...

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

- AMPYRA may cause serious side effects, including
- severe 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, or hives;
 - kidney or bladder infections.

The most common adverse events for AMPYRA in MS patients were urinary tract infection, trouble

sleeping, 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, and pain in your throat.

Please see the Patient Medication Guide on the following page.

You are encouraged to report negative side effects of prescription drugs to the FDA.

Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

To learn more at an educational event near you, visit AmpyraEvents.com.

MEDICATION GUIDE FOR AMPYRA® (am-PEER-ah) (dalfampridine) Extended Release Tablets

Read this Medication Guide before you start taking AMPYRA and each time you get a refill. There may be new information. This information does not take the place of talking with your doctor about your medical condition or your treatment.

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:

- have ever had a seizure
- 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?

Before you take AMPYRA, tell your doctor if you:

- have any other medical conditions
- are taking compounded 4-aminopyridine (fampridine, 4-AP)
- 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 59°F to 86°F (15°C to 30°C).
- Safely throw away AMPYRA that is out of date or no longer needed.

Keep AMPYRA and all medicines out of the reach of children.

General Information about the safe and effective use of AMPYRA

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use AMPYRA for a condition for which it was not prescribed. Do not give AMPYRA to other people, even if they have the same symptoms that you have. It may harm them.

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.

For more information, go to www.AMPYRA.com or call 1-800-367-5109.

What are the ingredients in AMPYRA?

Active ingredient: dalfampridine (previously called fampridine)

Inactive ingredients: colloidal silicon dioxide, hydroxypropyl methylcellulose, magnesium stearate, microcrystalline cellulose, polyethylene glycol, and titanium dioxide.

Distributed by: Acorda Therapeutics, Inc.

Ardsley, NY 10502

Issued 01/2014

This Medication Guide has been approved by the U.S. Food and Drug Administration.

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TREATMENT STRATEGIES FOR COGNITIVE SYMPTOMS IN MS

As noted earlier in this article, at least 50 percent of individuals with MS experience changes in cognition. This is often a challenging symptom that can impact one's life in many ways. For instance, some individuals with cognitive issues may reduce or discontinue their participation in outside activities, they may become less socially active, and employment is often affected.

At home, problems with cognition can also affect one's ability to perform everyday activities, as routine duties may take longer to complete, things may be forgotten, and stress may arise over these changes. Other symptoms of MS, such as fatigue and depression, may have a negative impact on cognition as well.

Treatment options and studies into potential new treatments are of constant interest and concern to the MS community. In this section, the possible benefits of exercise, medications, and cognitive rehabilitation are discussed.

Studies into Exercise and Cognition in MS

With or without MS, the positive effects of exercise on cognition are frequently mentioned in the news. The following data provide interesting information on different types of exercise when studied in individuals with MS and their effects on cognitive function.

Researchers from an Illinois study explain, "The current study compared the acute effects of moderate-intensity treadmill walking, moderate-intensity cycle ergometry, and guided yoga with those of quiet rest on executive

control in 24 persons with relapsing-remitting MS without impaired cognitive processing speed... The present results support treadmill walking as the modality of exercise that might exert the largest beneficial effects on executive control in persons with relapsing-remitting MS without impaired cognitive processing speed. This represents an exciting starting point for delineating the appropriate exercise stimulus (i.e., modality and intensity) for inclusion in a subsequent longitudinal exercise training intervention for improving cognitive performance in this population."

Investigators from Seattle report, "The present study adopted a randomized controlled trial design and examined the effect of a physical activity behavioral intervention on cognitive and walking performance among persons with MS who have mild or moderate disability status... The current study supports physical activity as a promising tool for managing cognitive impairment and impaired walking performance in persons with MS, and suggests that physical activity might have specific effects on cognition and non-specific effects on walking performance in this population."

Research in Seattle has also set out "to determine whether there is an association between improvements in objective measures of physical fitness and performance on cognitive tests in people with multiple sclerosis (MS)... Participants in the physically improved group demonstrated improved performance on

Continued on page 23

COMMON QUESTIONS AND ANSWERS REGARDING COGNITIVE ISSUES IN MS



Mrs. Angel Blair, M.A. is one of MSAA's Client Services Specialists. When asked about cognition as a symptom of MS, she talked about the experiences she has had with callers to MSAA's Helpline. First, Mrs. Blair provided examples of client calls and inquiries that she often receives in regards to this symptom. Common questions include:

Can MS affect cognition, memory, or judgment? Clients may report forgetfulness, not thinking as clearly or quickly as they once did, feelings of being overwhelmed, and not knowing if this is a symptom caused by their MS.

Are there ways to manage or treat this issue? Clients ask what they can do about these symptoms and who they can see for it.

Will MS affect their thinking? They want to know if this is something that will occur in the future.

Next, Mrs. Blair provided the types of information that she and other Client Services Specialists provide in response to these inquiries, as follows:

MS can have the ability to affect one's cognition – thinking, memory, decision

making, and judgment – especially in relation to where the disease is causing damage and inflammation in the brain. Other MS-symptom issues can also affect one's cognition, and these might include fatigue, problems in sleep management, and depression. The side effects of medication can also have an impact on cognition. Other factors that affect cognition include anemia, infection, and thyroid problems. This does not necessarily mean that every individual with MS will experience this symptom, as everyone's experience and symptom presentation with MS differs, but it is something that can occur as a challenge in the disease process.

Evaluating and considering all factors that could be involved in the appearance and/or worsening of this symptom is important, as other health conditions can occur in conjunction with MS and may be a contributing factor to difficulties in thinking or processing information. Talking to one's doctor can help to distinguish the cause of these changes.

In regard to symptom management and evaluations for cognitive issues, the first step

would be to work with his or her neurologist in discussing what these symptoms are, what's been noticed, what types of changes have occurred, and any other concerns one may have.

A neurologist may want to recommend **baseline cognitive evaluations and testing**, perhaps with the support of a neuropsychologist, who is a specialist focusing on mental processes, behavior, and thinking as they relate to the structure of the brain. This type of doctor can perform different types of testing in regards to one's current rate of processing thoughts and tasks. This testing can include a series of different tests to evaluate language, memory, organization, and similar types of functions.

After an evaluation, the specialist may then recommend and work with a client to create some type of **cognitive rehabilitation treatment plan**. This would include identifying problem areas and working on strategies for improvement in processing. Among other methods, this can include specific tasks and activities, games, exercise, and those types of things, all tailored to meet the client's specific needs.

Mrs. Blair also notes the possible impact that cognitive issues may have on daily life:

Cognitive challenges can interfere with daily tasks, such as household duties and responsibilities. For instance, memory issues and forgetfulness can cause problems when trying to complete chores or errands, making and keeping appointments, staying organized, and performing other daily activities.

Cognitive issues can impact one's employment and job responsibilities, if

memory and forgetfulness start to interfere with the completion of tasks. Decision making on the job can also be affected if one's judgment and executive function are at all compromised.

Management strategies may be developed to help someone who is having trouble at work as a result of cognitive problems caused by MS. Asking for accommodations in the workplace, if needed, can be very helpful. Another option is to take advantage of vocational rehabilitation services. These are specific counseling and employment-related services for those with disabilities – to identify areas of need and ways to manage and improve upon this issue.

Making lists, using files, or employing other organizational methods that help to keep things in order, both at work and a home, can assist individuals in accomplishing tasks and minimizing the effects of forgetfulness and other cognitive issues. If appropriate and as needed, asking for help to delegate tasks to others can be very helpful as well.

Communication is key. This includes having conversations with one's healthcare team and his or her family or support network to discuss cognitive issues, ways they can be managed, recommendations for treatment, and obstacles that may be modified to accommodate for these changes.

Cognitive difficulties can be a very sensitive and complicated issue to discuss with others, but it's important for individuals with MS and their families to know that they are not alone and there are supports in place to help people cope with this symptom.

Continued from page 19

measures of executive functioning after 12 weeks of exercise. The results of this study lend support to the hypothesis that change in fitness is associated with improved executive functioning in people with MS.”

Canadian researchers have found, “Exercise may have beneficial effects on both well-being and walking ability in multiple sclerosis (MS). Exercise is shown to be neuroprotective in rodents and may also enhance cognitive function in humans. It may, therefore, be particularly useful for MS patients with pronounced neurodegeneration...”

“Patients with progressive MS and moderate disability were randomized to one of three exercise interventions (arm ergometry, rowing, bicycle ergometry) for 8-10 weeks or a waitlist control group... Significant improvements were seen in aerobic fitness. In addition, exercise improved walking ability, depressive symptoms, fatigue and several domains of cognitive function. This study indicated that aerobic training is feasible and could be beneficial for patients with progressive MS. Larger exercise studies are needed to confirm the effect on cognition.”

Treatments with Medication

As discussed in MSAA's Winter/Spring 2013 issue of *The Motivator*, one of the best ways to maintain cognition is to do your best to avoid new lesions by taking a disease-modifying therapy (if you have a relapsing form of MS). A number of studies with these drugs have shown some benefit on protecting cognition. Twelve disease-modifying therapies are now approved for use by the United States Food and

Drug Administration (FDA) for relapsing forms of MS. Please visit MSAA's website at mysaa.org for specific information on these approved therapies.

People with MS and MS clinicians have hoped that medications such as those that help people with Alzheimer's disease might also benefit people with MS. Some of the Alzheimer's disease medications work to block the enzyme that breaks down the nerve signal messenger acetylcholine. Although early reports suggested that the medication Aricept® (donepezil) might help cognition in MS, more thorough research has not proven this drug to be of benefit.

Additional studies of the Alzheimer's medications Exelon® (rivastigmine) and Namenda® (memantine HCl) also did not demonstrate a clear benefit. Some side effects may include stomach or bowel problems, mood changes, and urinary difficulty. Others had hoped that the herbal extract ginkgo biloba would be of benefit, however, preliminary studies have not demonstrated a benefit. Many other supplements are often promoted to help memory in the general population, but hard data is very limited even for people without MS. Be sure to discuss any drugs or supplements you may be taking with your healthcare team.

Treating fatigue may reduce its effects, but does it help memory? This is a difficult area to study due to the difficulties in measuring and documenting cognitive changes, as well as the subjective nature of fatigue management. Small trials of amantadine (previously Symmetrel®) used for fatigue have not been convincing for cognitive improvement. The medication

Provigil® (modafinil) and Nuvigil® (armodafinil) are commonly used “off label” for MS fatigue and have also been used by some with attention disorders. Ampyra® (dalfampridine), studied in the 4-aminopyridine form also did not demonstrate improvement. Management of fatigue by both pharmacologic and non-pharmacologic means may be tried by some, and may include occupational therapy for energy-conservation techniques.”

Several medications are currently being evaluated for the treatment of cognitive dysfunction in MS. Many of the approved DMTs have ongoing studies to determine their effectiveness in reducing cognitive challenges. Other medications and supplements are in study phases as well. To view current studies in this area of research and possibly look into participating in a clinical trial, readers may visit clinicaltrials.gov and search for “cognition and MS” for a full listing of related studies.

Cognitive Rehabilitation and Retraining

This area of work is showing much potential for improvement in cognitive symptoms. Investigators and clinicians are able to address each type of dysfunction with various approaches to help people improve or compensate for any cognitive challenges they may experience.

Cognition covers several different areas or patterns of function. In general, these categories include: attention, memory, acquisition and retrieval, information-processing speed, and executive function. The type and severity of cognitive dysfunction that

an individual with MS experiences is largely dependent upon lesions occurring in certain regions of the brain, as well as areas of brain atrophy. Both the number of lesions (referred to as lesion load or burden) and atrophy (the shrinking of tissue or decrease in activity) are identified through neuroimaging techniques, such as a magnetic resonance imaging (MRI).

As mentioned earlier, a great deal of research continues to identify the specific areas of the brain that are affected by MS and lead to cognitive problems. Some studies have shown that brain atrophy, both regionally and globally, may contribute more to cognitive issues than the number of lesions. Noting that several areas of the brain may be affected, the effects of MS are thought to be widespread, and as a result, cognitive symptoms may be varied.

For this reason, cognitive rehabilitation specialists must conduct an extensive evaluation of their patients prior to and throughout the time they are in cognitive therapy. This enables the specialists to design the most appropriate treatment plans for their clients, and to revise these plans as needed throughout the rehabilitation period.

Initial Assessment for Cognitive Rehabilitation

An assessment or evaluation of the individual seeking treatment will include many important details, such as which types of neurocognitive symptoms (such as memory-retrieval problems) and neurobehavioral symptoms (such as reduced awareness and problem-solving issues) he or she is experiencing. Additional details include test data, background information from the

patient's neurologist or other treating physician, and historical information providing details about the individual prior to diagnosis.

The cognitive rehabilitation specialist will also note the patient's reactivity to emotional concerns, as well as other symptoms that may have an impact on cognition (such as fatigue and pain). Identifying one's abilities and preferences, along with learning about how he or she performs at school or at work, and in social situations, are also important while creating a customized treatment plan. Some of this information may be obtained through the family members and other individuals who are close with the patient. These people can also provide updates, letting the therapist know how the individual is doing in terms of applying the strategies and if any additional issues have been noted.

Additional testing may be required to help with the treatment plan. An occupational therapist may assess an individual's ability to perform activities of daily living. A speech-language pathologist may look for any deficits in areas of communication. Learning what the person with MS is able to do and what problems he or she may have is critical to the initial assessment.

Many of the techniques used for cognitive rehabilitation and retraining in MS originated with those used to assist individuals with traumatic brain injury (TBI). While the two conditions differ in many ways and the severity of symptoms can vary greatly within either disorder, the same theories may be applied to the similar challenges of cognitive dysfunction. Whether the goals are to provide prompts that help with memory, to clear away distractions to

increase attention, or to create more structure to improve executive function – or all three, along with many other strategies – these types of treatment plans are vital to improving one's cognitive performance and ultimately increasing one's quality of life.

Strategies for Problems with Memory and Learning

Although occasional forgetfulness, difficulties recalling specific names, or losing things is fairly common, real problems with memory and learning can become a huge hurdle in accomplishing tasks, succeeding at school or work, and even accomplishing activities of daily living. For some people with MS, the ability to sift through several ideas and identify the most important ones becomes significantly affected. These individuals may then be greatly challenged to recognize what needs to be remembered and then be able to store this information so it is easily retrievable when details need to be recalled.

One of the best methods for improving memory is to take notes; the value of doing so can't be overstated. Notes should be taken wherever and whenever information needs to be remembered – and this can include doctor appointments, school and work, at home, and while performing various activities such as shopping or attending meetings. The notes should be well-structured and kept in the same location, so they can always be immediately accessed.

Developing a system is important to make note-taking a part of the routine, and prompts should be included for both taking and

Continued on page 30

FOR RELAPSING FORMS OF
MULTIPLE SCLEROSIS (MS)

HEY MS,

TAKE THIS!

GILENYA CUTS RELAPSES IN HALF

Not actual patients.

Only GILENYA® combines proven efficacy to cut MS relapses in half vs a leading injectable in a once-daily* pill.

GILENYA reduced the frequency of relapses by 52% in a 1-year study vs Avonex®, and by 54% in a 2-year study vs placebo.

Indication

GILENYA is a prescription medicine used to treat relapsing forms of multiple sclerosis (MS) in adults. GILENYA can decrease the number of MS flare-ups (relapses). GILENYA does not cure MS, but it can help slow down the physical problems that MS causes.

Important Safety Information

You should not take GILENYA if in the last 6 months you experienced heart attack, unstable angina, stroke or warning stroke, or certain types of heart failure. Do not take GILENYA if you have an irregular

or abnormal heartbeat (arrhythmia), including a heart finding called prolonged QT as seen on an ECG, or if you take medicines that change your heart rhythm.

*GILENYA can result in a slow heart rate when first taken. You will be observed by a health care professional for at least 6 hours after you take your first dose. You may need to repeat this monitoring if you miss a dose.

Please see additional Important Safety Information on the next page and Brief Summary of Important Product Information on the following pages.



SPEAK UP TODAY!

Ask your doctor if GILENYA is right for you, and join the thousands of people already speaking out against their relapsing MS.



Important Safety Information

GILENYA may cause serious side effects such as:

- Slow heart rate, especially after first dose. You will be monitored by a health care professional for at least 6 hours after your first dose. Your pulse and blood pressure will be checked hourly. You'll get an ECG before and 6 hours after your first dose. If any heart problems arise or your heart rate is still low, you'll continue to be monitored. If you have any serious side effects, especially those that require treatment with other medicines, or if you have certain types of heart problems, or if you're taking medicines that can affect your heart, you'll be watched overnight. If you experience slow heart rate, it will usually return to normal within 1 month. Call your doctor, or seek immediate medical attention if you have any symptoms of slow heart rate, such as feeling dizzy or tired or feeling like your heart is beating slowly or skipping beats. Symptoms can happen up to 24 hours after the first dose. Do not stop taking GILENYA without consulting with your doctor. Call your doctor if you miss 1 or more doses of GILENYA—you may need to repeat the 6-hour monitoring.
- Increased risk of serious infections. GILENYA lowers the number of white blood cells (lymphocytes) in your blood. This will usually go back to normal within 2 months of stopping GILENYA. Your doctor may do a blood test before you start GILENYA. GILENYA may decrease the way vaccines work in your body, especially the chicken pox vaccine. Increased risk of infection was seen with doses higher than the approved dose (0.5 mg). Two patients died who took higher-dose GILENYA (1.25 mg) combined with high-dose steroids. Call your doctor right away if you have fever, tiredness, body aches, chills, nausea, or vomiting.
- Macular edema, a vision problem that can cause some of the same vision symptoms as an MS attack (optic neuritis), or no symptoms. If it happens, macular edema usually starts in the first 3 to 4 months after starting GILENYA. Your doctor should test your vision before you start GILENYA; 3 to 4 months after you start GILENYA; and any time you notice vision changes. Vision problems may continue after macular edema has gone away. Your risk of macular edema may be higher if you have diabetes or have had an inflammation of your eye (uveitis). Call your doctor right away if you have blurriness, shadows, or a blind spot in the center of your vision; sensitivity to light; or unusually colored vision.
- Narrowing or blockage of the blood vessels in your brain may lead to an interrupted blood supply or bleeding into your brain. Call your doctor right away if you experience any symptoms, such as sudden headache, confusion, seizures, loss of vision, or weakness.
- Breathing problems. Some patients have shortness of breath. Call your doctor right away if you have trouble breathing.
- Liver problems. Your doctor should do blood tests to check your liver before you start GILENYA. Call your doctor right away if you have nausea, vomiting, stomach pain, loss of appetite, tiredness, dark urine, or if your skin or the whites of your eyes turn yellow.
- Increases in blood pressure (BP). BP should be monitored during treatment.

GILENYA may harm your unborn baby. Talk to your doctor if you are pregnant or planning to become pregnant. Women who can become pregnant should use effective birth control while on GILENYA, and for at least 2 months after stopping. If you become pregnant while taking GILENYA, or within 2 months after stopping, tell your doctor right away. Women who take GILENYA should not breast-feed, as it is not known if GILENYA passes into breast milk. A pregnancy registry is available for women who become pregnant during GILENYA treatment. For more information, you can contact the GILENYA Pregnancy Registry by calling Outcome at 1-877-598-7237, by sending an e-mail to gpr@outcome.com, or by going to www.gilenyapregnancyregistry.com.

Tell your doctor about all your medical conditions, including if you had or now have an irregular or abnormal heartbeat; heart problems; a history of repeated fainting; a fever or infection, or if you are unable to fight infections due to a disease or are taking medicines that lower your immune system; eye problems; diabetes; breathing or liver problems; or uncontrolled high blood pressure. Also tell your doctor if you have had chicken pox or have received the chicken pox vaccine. Your doctor may test for the chicken pox virus, and you may need to get the chicken pox vaccine and wait 1 month before starting GILENYA.

If you take too much GILENYA, call your doctor or go to the nearest hospital emergency room right away.

Tell your doctor about all the medicines you take or have recently taken, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Especially tell your doctor if you take medicines that affect your immune system, or have taken them in the past. Tell your doctor if you have been vaccinated within 1 month before you start taking GILENYA. You should not get certain vaccines while taking GILENYA and for at least 2 months after stopping GILENYA treatment.

The most common side effects with GILENYA were headache, flu, diarrhea, back pain, abnormal liver tests, and cough.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.



Please see Brief Summary of Important Product Information on next pages.

MEDICATION GUIDE
GILENYA® (je-LEN-yah)
(fingolimod)
capsules

Read this Medication Guide before you start using Gilenya and each time you get a refill. There may be new information. This information does not take the place of talking with your doctor about your health problem or treatment.

What is the most important information I should know about GILENYA?

GILENYA may cause serious side effects, including:

1. Slow heart rate (bradycardia or bradyarrhythmia) when you start taking GILENYA. GILENYA can cause your heart rate to slow down, especially after you take your first dose. You will have a test to check the electrical activity of your heart (ECG) before you take your first dose of GILENYA.

You will be observed by a healthcare professional for at least 6 hours after you take your first dose of GILENYA.

After you take your first dose of GILENYA:

- Your pulse and blood pressure should be checked every hour.
- You should be observed by a healthcare professional to see if you have any serious side effects. If your heart rate slows down too much, you may have symptoms such as:
 - dizziness
 - tiredness
 - feeling like your heart is beating slowly or skipping beats
- If you have any of the symptoms of slow heart rate, they will usually happen during the first 6 hours after your first dose of GILENYA. Symptoms can happen up to 24 hours after you take your first GILENYA dose.
- 6 hours after you take your first dose of GILENYA you will have another ECG. If your ECG shows any heart problems or if your heart rate is still too low or continues to decrease, you will continue to be observed.
- If you have any serious side effects after your first dose of GILENYA, especially those that require treatment with other medicines, you will stay in the medical facility to be observed overnight. You will also be observed for any serious side effects for at least 6 hours after you take your second dose of GILENYA the next day.
- If you have certain types of heart problems, or if you are taking certain types of medicines that can affect your heart, you will be observed overnight after you take your first dose of GILENYA.

Your slow heart rate will usually return to normal within 1 month after you start taking GILENYA. Call your doctor or go to the nearest hospital emergency room right away if you have any symptoms of a slow heart rate.

If you miss 1 or more doses of GILENYA you may need to be observed by a healthcare professional when you take your next dose. Call your doctor if you miss a dose of GILENYA. See **“How should I take GILENYA?”**

2. Infections. GILENYA can increase your risk of serious infections and decrease the way vaccines work in your body to prevent certain diseases, especially the chicken pox vaccine. GILENYA lowers the number of white blood cells (lymphocytes) in your blood. This will usually go back to normal within 2 months of stopping treatment. Your doctor may do a blood test before you start taking GILENYA. Call your doctor right away if you have any of these symptoms of an infection:

- fever
- tiredness
- body aches
- chills
- nausea
- vomiting

3. A problem with your vision called macular edema. Macular edema can cause some of the same vision symptoms as an MS attack (optic neuritis). You may not notice any symptoms with macular edema. If macular edema happens, it usually starts in the first 3 to 4 months after you start taking

GILENYA. Your doctor should test your vision before you start taking GILENYA and 3 to 4 months after you start taking GILENYA, or any time you notice vision changes during treatment with GILENYA. Your risk of macular edema may be higher if you have diabetes or have had an inflammation of your eye called uveitis.

Call your doctor right away if you have any of the following:

- blurriness or shadows in the center of your vision
- a blind spot in the center of your vision
- sensitivity to light
- unusually colored (tinted) vision

What is GILENYA?

GILENYA is a prescription medicine used to treat relapsing forms of multiple sclerosis (MS) in adults. GILENYA can decrease the number of MS flare-ups (relapses). GILENYA does not cure MS, but it can help slow down the physical problems that MS causes.

It is not known if GILENYA is safe and effective in children under 18 years of age.

Who should not take GILENYA?

Do not take GILENYA if you:

- have had a heart attack, unstable angina, stroke or warning stroke or certain types of heart failure in the last 6 months
- have certain types of irregular or abnormal heartbeat (arrhythmia), including patients in whom a heart finding called prolonged QT is seen on ECG before starting GILENYA
- are taking certain medicines that change your heart rhythm

If any of the above situations apply to you, tell your doctor.

What should I tell my doctor before taking GILENYA?

Before you take GILENYA, tell your doctor about all your medical conditions, including if you had or now have:

- an irregular or abnormal heartbeat (arrhythmia)
- a history of stroke or warning stroke
- heart problems, including heart attack or angina
- a history of repeated fainting (syncope)
- a fever or infection, or you are unable to fight infections due to a disease or taking medicines that lower your immune system. Tell your doctor if you have had chicken pox or have received the vaccine for chicken pox. Your doctor may do a blood test for chicken pox virus. You may need to get the vaccine for chicken pox and then wait 1 month before you start taking GILENYA.
- eye problems, especially an inflammation of the eye called uveitis.
- diabetes
- breathing problems, including during your sleep
- liver problems
- high blood pressure
- Are pregnant or plan to become pregnant. GILENYA may harm your unborn baby. Talk to your doctor if you are pregnant or are planning to become pregnant.
 - Tell your doctor right away if you become pregnant while taking GILENYA or if you become pregnant within 2 months after you stop taking GILENYA.
 - If you are a female who can become pregnant, you should use effective birth control during your treatment with GILENYA and for at least 2 months after you stop taking GILENYA.

Pregnancy Registry: There is a registry for women who become pregnant during treatment with GILENYA. If you become pregnant while taking GILENYA, talk to your doctor about registering with the GILENYA Pregnancy Registry. The purpose of this registry is to collect information about your health and your baby's health.

For more information, contact the GILENYA Pregnancy Registry by calling Outcome at 1-877-598-7237, by sending an email to gpr@outcome.com, or go to www.gilenyapregnancyregistry.com.

- Are breastfeeding or plan to breastfeed. It is not known if GILENYA passes into your breast milk. You and your doctor should decide if you will take GILENYA or breastfeed. You should not do both.

Tell your doctor about all the medicines you take or have recently taken, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Especially tell your doctor if you take medicines that affect your immune system, or have taken them in the past.

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

Using GILENYA and other medicines together may affect each other causing serious side effects.

Especially tell your doctor if you take vaccines. Tell your doctor if you have been vaccinated within 1 month before you start taking GILENYA. You should not get certain vaccines while you take GILENYA and for at least 2 months after you stop taking GILENYA. If you take certain vaccines, you may get the infection the vaccine should have prevented. Vaccines may not work as well when given during GILENYA treatment.

How should I take GILENYA?

- You will be observed by a healthcare professional for at least 6 hours after your first dose of GILENYA. See **“What is the most important information I should know about GILENYA?”**
- Take GILENYA exactly as your doctor tells you to take it.
- Take GILENYA 1 time each day.
- If you take too much GILENYA, call your doctor or go to the nearest hospital emergency room right away.
- Take GILENYA with or without food.
- Do not stop taking GILENYA without talking with your doctor first.
- Call your doctor right away if you miss a dose of GILENYA. You may need to be observed by a healthcare professional for at least 6 hours when you take your next dose. If you need to be observed by a healthcare professional when you take your next dose of GILENYA you will have:
 - an ECG before you take your dose
 - hourly pulse and blood pressure measurements after you take the dose
 - an ECG 6 hours after your dose
- If you have certain types of heart problems, or if you are taking certain types of medicines that can affect your heart, you will be observed overnight by a healthcare professional in a medical facility after you take your dose of GILENYA.
- If you have serious side effects after taking a dose of GILENYA, especially those that require treatment with other medicines, you will stay in the medical facility to be observed overnight. If you were observed overnight, you will also be observed for any serious side effects for at least 6 hours after you take your second dose of GILENYA. See **“What is the most important information I should know about GILENYA?”**

What are possible side effects of GILENYA?

GILENYA can cause serious side effects.

See **“What is the most important information I should know about GILENYA?”**

Serious side effects include:

- **swelling and narrowing of the blood vessels in your brain that may lead to a stroke or bleeding.** This problem usually gets better when you stop taking GILENYA. Call your doctor right away if you have any of the following symptoms of a stroke or bleeding in your brain, including:

- sudden headache
- confusion
- seizures
- loss of vision
- weakness
- **breathing problems.** Some people who take GILENYA have shortness of breath. Call your doctor right away if you have trouble breathing.
- **liver problems.** GILENYA may cause liver problems. Your doctor should do blood tests to check your liver before you start taking GILENYA. Call your doctor right away if you have any of the following symptoms of liver problems:
 - nausea
 - vomiting
 - stomach pain
 - loss of appetite
 - tiredness
 - your skin or the whites of your eyes turn yellow
 - dark urine

The most common side effects of GILENYA include:

- headache
- flu
- diarrhea
- back pain
- abnormal liver tests
- cough

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

These are not all of the possible side effects of GILENYA. For more information, ask your doctor or pharmacist. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How do I store GILENYA?

- Store GILENYA in the original blister pack in a dry place.
- Store GILENYA at room temperature between 59°F to 86°F (15°C to 30°C).
- Keep GILENYA and all medicines out of the reach of children.

General information about GILENYA

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use GILENYA for a condition for which it was not prescribed. Do not give GILENYA to other people, even if they have the same symptoms you have. It may harm them.

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

For more information, go to www.pharma.US.Novartis.com or call 1-888-669-6682.

What are the ingredients in GILENYA?

Active ingredient: fingolimod

Inactive ingredients: gelatin, magnesium stearate, mannitol, titanium dioxide, yellow iron oxide.

This Medication Guide has been approved by the U.S. Food and Drug Administration.

GILENYA is a registered trademark of Novartis AG.

Manufactured by: Novartis Pharma Stein AG
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East Hanover, New Jersey 07936

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Q&A

WITH A SPEECH LANGUAGE PATHOLOGIST

Carrie Bruce, PhD, CCC-SLP

Senior Research Scientist, Center for Assistive Technology and Environmental Access at Georgia Tech
Member, MSAA Healthcare Advisory Council



What type of therapist(s) can assist with the diagnosis and treatment of cognitive issues with MS?

“When an individual with MS is experiencing some type of cognitive dysfunction, he or she would most often contact a clinical psychologist, neuropsychologist, occupational therapist, and/or speech-language pathologist.”

In general, how often might someone need to see a therapist, and does insurance usually pay for such appointments?

“It really depends on the focus of treatment, but most often cognitive rehabilitation works best when people participate on a frequent basis. The challenge in providing services is that it mostly results in few options for insurance coverage. Most insurance companies do not cover cognitive rehab services for people who experience deficits as a result of a non-acute neurological condition, including chronic diseases such as multiple sclerosis (and others such as congestive heart failure, autism, cerebral palsy, chronic obstructive pulmonary disease, or post chemotherapy). The research on the

effectiveness of cognitive rehabilitation for MS that is used for coverage determination with most of the insurance companies reflects that it is experimental or that it does not have enough evidence to demonstrate medical necessity.”

Do you have any personal thoughts or guidance that you would want to give anyone with MS who may be experiencing cognitive issues?

“I would recommend for the individual to have a discussion with his or her medical provider first to review the list of medications to determine the impacts these may have on cognitive function. The medical provider can also discuss other potential sources of cognitive issues, such as nutritional deficits, poor sleep habits or sleep disorders, stress, etc. Individuals should be sure to talk with their medical provider before trying any alternative supplement that promises improvement in memory or other cognitive function. People experiencing cognitive issues should still try to maintain social connections and outlets that keep them mentally active and challenge their memory, attention, language, and problem-solving abilities.”

reviewing notes regularly. Using a Day Planner-type of booklet or smartphone is ideal for keeping things organized. Dividing the information into smaller sections and practicing by re-reading and/or reading aloud helps to better store the information and enable one to retrieve the information when needed.

Improving Information-Processing Speed

When information cannot be processed quickly, many functions such as social interactions and day-to-day activities are affected. Having a conversation can become labored and uncomfortable; trying to follow directions can at times be almost impossible; and having to think of more than one or two concepts at the same time can lead to frustration and confusion. Fortunately, people who experience reduced information-processing speed may take steps to help minimize the effects of this type of dysfunction.

Consciously increasing one's attention on the task, on the person speaking, or on whatever the event may be, while reducing any distractions, are good first steps (strategies for improving attention are noted in the next section). Another helpful tip is to take notes and ask questions – when appropriate – to assist with comprehension and understanding.

Additionally, using different forms of communication to reinforce the same information can also assist with speedier comprehension and retrieval. This might include seeing things visually (through attending an event, as well as viewing videos, charts, outlines, etc.), hearing the information presented either in person or on a recording, and written information, which includes asking

people to email main points as a follow-up to a lecture or reviewing notes from the event.

Addressing Issues with Attention

Without the ability to focus and provide uninterrupted attention, one's ability to listen, learn, and retain information is immediately compromised. Perhaps the most important strategy for improving attention is to reduce or eliminate any distractions. This may be accomplished by looking at the area where attention is needed and evaluating potential distractions. Whether they consist of sight or sound – necessary steps should be taken to reduce or eliminate these diversions. Examples include cleaning away extra clutter from a room, reducing the number of people present during a gathering, and/or turning off the TV and other electronic devices. Earplugs or headphones may also be used if needed to reduce noise or other competing distractions.

Sometimes people have thoughts that interfere with attention to the matter at hand. With this type of distraction, a good plan is to write down any ideas that might be monopolizing one's thoughts and try to set them aside to focus on at a later time.

Attention may also be improved through identifying, organizing, and scheduling tasks and activities. This type of cognitive rehabilitation enables someone to perform daily functions efficiently and minimize how often he or she needs to shift attention to switch directions or return to repeat an action.

Improving Executive Function

Instruction on how to become better organized and step-by-step plans on how to

start and complete projects are key strategies for improving one's ability to employ good judgement and be able to solve problems efficiently. Structuring one's schedule with reasonable timing to complete different projects can help to avoid becoming overwhelmed with everything that needs to be done.

To reduce the pressure of working under a tight deadline, individuals may want to double or triple their estimate of time required, just to avoid any extra stress. This is partly due to the fact that people with MS sometimes feel that their sense of time is diminished, and duties might be more time-consuming due to fatigue and other factors. Scheduling time to work when interruptions are at a minimum is also important.

Individuals with MS who experience problems with executive function need to be flexible with their schedule. While staying on track is worthwhile, people with MS need to be prepared for changes in symptoms that may disrupt their plans for the day, week, or potentially longer. Even when not experiencing any type of changes in symptoms, schedules should be regularly re-evaluated and revised as needed. Individuals should also be aware of their own physical limits as well as the fact that they may be more easily distracted now than prior to their diagnosis.

Increased Awareness and Continued Learning

Individuals with MS who are experiencing cognitive difficulties may benefit greatly by staying aware of their limitations and continually learning new ways to counter the effects of this challenging symptom. Through

the knowledge that cognitive issues could be slowing them down, causing frustration and forgetfulness, as well as other implications, individuals may be empowered by regularly learning and employing new techniques. Doing so can lead to a better quality of life and even greater success with their endeavors.

Furthermore, relationships may become more positive as plans are put into place to counter any problem areas. Other urgent responsibilities, such as taking one's medications at the correct times and dosages, may be more closely followed through planning, organization, and the added attention the individual knows is necessary.

Closing Notes

When asked about cognitive problems experienced by people with MS, MSAA Chief Medical Officer Jack Burks, MD, reflects on the many challenges that some individuals with MS may face while coping with this often unexpected symptom. At the same time, he is pleased to explain that several proven strategies, as well as new and emerging therapies, are becoming available, all of which may provide the help needed to counter these types of symptoms.

Dr. Burks explains, "Many people with MS tend to focus on their physical challenges and minimize or deny their cognitive issues, although they may realize some difficulties at work, at home, or with social interactions. Their adherence to MS medications may also suffer.

"When finally evaluated by neuropsychological testing, they are often surprised by the degree of difficulties they experience during

the tests. They often believe that if they look and feel ‘pretty good,’ drive safely, get satisfactory job performance evaluations, and can handle their checkbook, they must not be cognitively impaired. Once the problem is identified, they are initially upset. However, after they learn how to deal with the issues, they are relieved by the ability to accomplish even more.

“The bottom line is that cognitive problems may exist... but so do many opportunities and strategies that are available to help people perform their cognitive tasks. This article provided insights into the enormous research efforts related to MS cognition and ideas to improve one’s daily living skills. Additionally, we are learning that MS disease-modifying therapies may also help MS cognition, which is good news of course for individuals with

relapsing forms of MS. However, some medications are now being studied for cognition in individuals with progressive forms of MS, which is certainly good news for individuals with this type of MS as well.” ♦

Cognitive rehabilitation and retraining offers many valuable strategies for achieving goals and attaining optimum quality of life. With this in mind, anyone who believes that he or she may be experiencing changes in cognitive function is encouraged to consult his or her neurologist about the potential benefits that this type of therapy may provide.

RESOURCES

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Stem-Cell Therapy?



Dr. Jack Burks

Q: I was diagnosed with RRMS in August 2011. My baseline has been good and my neurologist said I would benefit from stem-cell therapy, but my internal medicine doctor said I don't need it. Why would my internal

medicine doctor not want to help me achieve my goal of returning to normal health?

A: I will answer this with my short “bottom line” opinion. Although new, experimental trials with stem-cell therapy are encouraging, many questions remain. If and when stem-cell therapy research becomes conclusive and FDA-approved, you and your doctors will be able to make more informed decisions based on the potential benefits and risks.

While we often see news about stem-cell therapy in the media, it is still in very early phases of study. On the one hand, presently approved disease-modifying therapies have all been tested for many years – decades for some – with thousands of patients. On the other hand, stem-cell therapy has only been studied in recent years and only with limited numbers of patients. We also hear about individuals having little or no new disease activity following stem-cell therapy, but at the same time, we hear about other individuals who experienced severe and even life-threatening adverse events from this experimental treatment.

For these reasons, I do not have enough information (data) to recommend stem-cell therapy at this time. While I am optimistic that it may hold promise, it is “not ready for prime time,” until additional experimental trials are conducted and more evidence of both effectiveness and safety is shown. Your doctor is undoubtedly aware of the status of stem-cell research and is waiting until enough positive data are available and the FDA approves this therapy. In the meantime, I give the stem-cell researchers and the brave MS patients in the trials my admiration and best wishes for speedy answers. For more information on stem-cell research, please see page 40.

Q: I have had MS for 30 years and I am 68 years old. I use a wheelchair since I can't stand or walk. I am able to use my arms, hands, and eyes, and I feel fortunate for this. However, I have one problem that really annoys me: I get hot spells that last an hour or even longer. They're not hot flashes. I've asked my doctors, including my neurologist, and they don't have any answers. Is this something that is MS-related? I'd like to figure out why I have these hot spells and what I can do to alleviate them.

A: “Hot Spells” lasting an hour or more must be terribly uncomfortable. They could be related to MS, or they could be caused by a different issue. I sent your question to some of my senior MS colleagues for their experiences

and advice. My thanks go to Drs. Randall Schapiro and Donald Barone, eminent MS experts and members of MSAA's Healthcare Advisory Council (HAC).

“Hot spell” symptoms, seen in a few MS patients, are not related to the type of “hot flashes” seen with menopause. In MS, they are usually less than an hour in duration, are not very frequent, are only mildly uncomfortable, and do not usually require treatment. They fall into the catalog of MS symptoms named “paroxysmal dysautonomia.” Paroxysmal dysautonomia is an intermittent dysfunction of the body's autonomic nervous system, which may cause the symptom of intermittent hot sensations for MS patients. Treatment, while not often needed, may include seizure medication such as carbamazepine, gabapentin, pregabalin, valproate, lamotrigine, and others. If not successful, your doctor may consider beta blockers and calcium channel blockers. I mention these medications if needed to help guide your treating physician.

One precaution: My colleagues both recommended an evaluation for non-MS causes such as endocrinopathies, carcinoid syndrome, and pheochromocytoma. These are three uncommon conditions of the metabolic system in the body that may cause flushing episodes. They are usually associated with many other symptoms that you do not seem to have. Again, please share this detailed medical opinion with your doctor and I wish you success in your search for relief.

Q: I was diagnosed with MS in October 2007 after I had a stroke. In 2013, I began having problems with double vision. How can I prevent/improve this?

A: In the cover story of the Winter/Spring 2013 issue of *The Motivator*, visual problems were discussed in depth, since these are a major concern for many people with MS. To follow are excerpts from that section of the article, which you may find helpful in your treatment plan.

“Many functions are involved in seeing an object. Two major components needed for effective vision are (1) the ability to correctly image what is seen and (2) the proper coordination of the muscles that surround the eye and control its movements. Either or both of these functions can be affected by MS.

“The most common problems are decreased or blurred vision (caused by *optic neuritis*), double vision (*diplopia*), and shaking, involuntary movements of the eyes (*nystagmus*). While optic neuritis results from inflammation and demyelination along the optic nerve, double vision and involuntary eye movements are the result of lesions in the brain stem, a part of the nervous system between the brain and cervical spinal cord.

“Diplopia, also known as ‘double vision,’ occurs when the muscles that control a particular eye movement are weakened and not coordinated. Although annoying, double vision usually resolves on its own without medical treatment. When diplopia comes on suddenly, it could indicate an acute attack.

“Whenever a visual problem arises, an ophthalmologist or neuro-ophthalmologist should be consulted. At times, the doctor may decide that the best treatment is to wait for the inflammation to go down and to see if the visual symptoms disappear on their own,

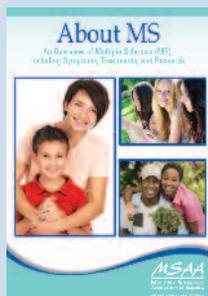
reserving steroid treatment for more severe attacks. Other doctors may treat the relapse with steroids immediately.

“If the symptoms are severe, intravenous steroid treatment may be used to reduce the inflammation and accelerate the recovery process. The same steroid treatment used to treat other types of MS relapses is often effective in shortening the duration of visual problems. These are usually given via intravenous injection (IV) for a few days, but steroids may also be given orally. An example of high dose steroids would be 1,000 mg of Solu-Medrol® (IV methylprednisolone).

“Another line of action is through disease-modifying therapies (DMTs). Presently, 12 disease-modifying therapies are FDA-approved for treating the relapsing forms of MS. Several studies have shown that these can reduce the number and severity of attacks, which in turn reduces the development of visual difficulties.

“Several non-pharmaceutical options are also available to help cope with visual changes. For instance, an eye patch is sometimes used to treat diplopia (double vision) when necessary, such as when driving or reading. An ophthalmologist may also offer additional ideas or treatments for specific visual symptoms.

Learn More About MS!



To order your free copy of MSAA's About MS booklet, please visit mysaa.org/publications or call (800) 532-7667.

To Submit Questions...

Please submit your questions to:

MSAA
Questions for Ask the Doctor
c/o Dr. Jack Burks
706 Haddonfield Road
Cherry Hill, New Jersey 08002

Readers may also send in questions via email to askdr@mysaa.org. Please be sure to write "Ask the Doctor" in the subject line.

“Individuals with MS experiencing visual problems are often comforted by the fact that these symptoms are usually temporary. As with other MS symptoms, as noted earlier, please keep in mind that visual problems in MS may also be worsened by stress, fatigue, infection, certain medications, or an increase in temperature. When possible, avoiding situations that could worsen the symptoms of MS will also help to minimize the occurrence of visual issues.”

Please note that the information on visual problems is from the Winter/Spring 2013 issue of The Motivator and was reviewed and edited by Robert K. Shin, MD. To view the article online, please go to mysaa.org, select the Winter/Spring 2013 cover story under publications, and go to the section of the article on visual problems. ♦

Jack Burks, MD is the chief medical officer for MSAA. He is an international MS neurologist, writer, lecturer, and researcher, who assists with the development of new MS therapies and advises patients, families, MS organizations, and healthcare groups. Dr. Burks is a clinical professor of neurology at the Florida International University in Miami and has authored textbooks, chapters, and articles on MS.

Changes Made to Tecfidera's Label

In December 2014, the United States Food and Drug Administration (FDA) made some changes to the product labeling for Tecfidera® (dimethyl fumarate). These changes instruct physicians on how to best prescribe the drug for their patients to minimize the potential for certain side effects and adverse events.

To follow is a general overview of the changes to Tecfidera's labeling:

- **Temporary dose reductions** (to half the dose) may be used for individuals unable to tolerate the drug, for up to four weeks before returning to the full dose
- **Discontinuation should be considered** for patients unable to return to the maintenance dose after four weeks of a reduced dose
- **Non-enteric, coated aspirin** (up to a dose of 325 mg), 30 minutes prior to Tecfidera dosing, may be given to help reduce the potential side effect of flushing
- **This medication is contraindicated** in patients with known hypersensitivity to dimethyl fumarate or to any of Tecfidera's ingredients

- **New warning that anaphylaxis and angioedema (allergic reactions) may occur** after the first dose or at any time during treatment; symptoms have included difficulty breathing, urticaria [hives], and swelling of the throat and tongue; Tecfidera should be discontinued and immediate medical care sought if experiencing these symptoms
- **A fatal case of Progressive Multifocal Leukoencephalopathy (PML)** occurred in one patient with MS who received Tecfidera for four years while enrolled in a clinical trial; the patient experienced prolonged lymphopenia (reduction in circulating lymphocytes) while taking Tecfidera
- **New warning that Tecfidera may decrease lymphocyte counts**; a CBC (complete blood count), including lymphocyte count, should be obtained before initiating treatment, after six months of treatment, every six to 12 months thereafter, and as clinically indicated

Please note that these are only highlights of the labeling changes for Tecfidera. For full drug and prescribing information, please visit Tecfidera's website at www.tecfidera.com. ♦

Editor's note: In our Research News column, we strive to include any major MS news that has occurred since our previous issue of The Motivator was published. Although much of the information is no longer considered "breaking news," it is still information that is vital to the MS community and was not available until after the issue date of our last magazine. More information about all of these topics (other than the entry on stem-cell research) may be found on MSAA's website, mysaa.org, under "News from MSAA." More information is available on stem-cell research in MSAA's 2015 MS Research Update publication.

Lemtrada™ Receives FDA Approval for Relapsing Forms of MS

On November 14, 2014, the United States Food and Drug Administration (FDA) announced that Lemtrada™ (alemtuzumab) had been approved for the long-term treatment of relapsing forms of multiple sclerosis (MS). Lemtrada is a humanized monoclonal antibody that targets a protein present on the surface of mature lymphocytes, and results in a rapid depletion/suppression of T and B cells. By doing so, researchers believe that the immune system may be reset, and the new immune-system cells may behave differently than those that previously attacked the nerves.

Given via intravenous (IV) infusion for a course of five days and followed one year later by a second three-day course, Lemtrada has been approved as a second-line therapy. This classification refers to a drug that may only be prescribed when other FDA-approved treatments fail or are not tolerated well by a patient. Because of the medication's safety profile, Lemtrada should generally be prescribed for patients who have had an inadequate response to two or more of the disease-modifying therapies.

In clinical trials, Lemtrada was shown to significantly reduce the relapse rate for individuals with relapsing-remitting MS, as well as significantly reduce the risk of sustained disability accumulation. In a multi-year extension study of the 334 individuals who participated in the original Phase II study (comparing Lemtrada to an approved long-term treatment for MS), Lemtrada reduced the risk for sustained accumulation of disability by

73 percent, while 77 percent of Lemtrada-treated patients were relapse-free. A five-year assessment showed that 87 percent were free of sustained disability accumulation, 72 percent were relapse-free, and 65 percent were free of clinical-disease activity.

Adverse events from Lemtrada can include infusion reactions to the medication, an increased risk of infection, and emergent autoimmune diseases. In the two Phase III studies – CARE-MS I and II respectively – approximately 18 percent and 16 percent of Lemtrada patients developed an autoimmune thyroid disorder, and 0.8 percent and 1 percent developed a potentially severe bleeding disorder called immune thrombocytopenic purpura (ITP). In ITP, the blood does not clot as it should, and this can result in internal bleeding.

Because of its potential adverse events, Lemtrada is only available through the Lemtrada REMS (Risk Evaluation and Mitigation Strategy) program. This program has been developed to ensure that access to Lemtrada in the U.S. is only through certified prescribers, healthcare facilities and specialty pharmacies and to also ensure that patients are enrolled in the REMS program. The program helps to educate healthcare providers and patients on the serious risks associated with Lemtrada and the appropriate periodic monitoring required.

For more information, readers may call the MS One to One® line at (855) MSOne2One [(855) 676-6326]. Information and support are also available at www.MSOnetoOne.com. ♦

Phase II Primary-Progressive MS Study Does Not Meet Primary Endpoint

On December 1, 2014, Novartis announced that their Phase III INFORMS trial with Gilenya® (fingolimod) for individuals with primary-progressive multiple sclerosis (PPMS) did not meet its primary endpoint. Presently, this disease-modifying therapy, taken orally (by mouth), is approved for the long-term treatment of relapsing forms of MS.

According to a press release from Novartis, the INFORMS study is the largest clinical trial ever conducted in PPMS, enrolling 970 people aged 25-69 years with PPMS. The double-blind, randomized, and placebo-controlled

study was conducted at 148 sites across 18 countries.

Patients were treated for at least three years and the primary endpoint was to evaluate the effect of Gilenya versus placebo on reducing the risk of three-month sustained disability progression. Unfortunately, the initial results of the study did not show a significant difference between the group taking Gilenya and the placebo group. However, additional analysis of the data will reveal if any sub-groups of individuals with PPMS experienced positive effects from this medication over the three years. ♦

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Stem-Cell Research Update

Even though it is still in early stages of study, the topic of stem-cell research in MS has been growing in popularity within the MS community. According to MSAA's 2015 edition of the *MS Research Update*, stem-cell approaches are based on three different classes. To follow is an overview of these approaches, along with a few recent study results:

Hematopoietic Stem-Cell Transplantation (HSCT)

This form of stem-cell therapy first requires a wiping out or “ablation” of the immune system, typically with high-dose chemotherapy. This destroys most blood cells as well as the bone marrow, where blood cells are formed. Then a patient's own hematopoietic stem cells can be transplanted, in an effort to completely reset the immune system in the hopes of abolishing the autoimmunity responsible for MS.

One trial of this technique is the High-Dose Immunosuppression and Autologous (stem cell) Transplantation for Multiple Sclerosis (HALT MS) Study, for poor prognosis multiple sclerosis. The two-year follow-up results of this Phase II study with 25 patients reported that the treatment induced profound immune suppression and a high rate of sustained remissions at two years.

Further interim results covering three years of the study reported that 78 percent of subjects had no new disease activity; however, treatment failed in five subjects and two deaths occurred. There have been 130 adverse events that were severe or life-threatening, most relating to low blood counts induced by the treatment approach.

A Swedish study of 41 patients with aggressive, relapsing forms of MS, found that a high proportion were free from disease activity following hematopoietic stem-cell transplantation (HSCT). With a mean average follow-up time of nearly four years after receiving the HSCT procedure, 89 percent of the participants were relapse-free and 77 percent of the participants had no disability progression. Serious side effects included sepsis, fever, and other adverse events. These included a reactivation of herpes zoster in seven patients and thyroid disease in four patients; no deaths occurred in this trial.

Therapy Utilizing Mesenchymal Stem Cells

These stem cells can be derived from tissues other than bone marrow and do not require a “wiping out” of the immune system. In a Phase IIa study, 10 patients with SPMS with involvement of the visual system were infused with self-derived (autologous) mesenchymal stem cells. Researchers found an improvement in visual and other measures of optic-nerve function. There were no serious adverse events or deaths. The results of this study were suggestive of a more generalized neuroprotective effect.

Therapy Utilizing Stem Cells to Directly Regenerate Myelin

This third approach is perhaps the one most in-line with the notions about the potential uses of stem cells. This approach requires multiple complex steps in order to be successful. Techniques must be employed to: harvest a patient's stem cells; grow and multiply them;

administer them to the patient; ensure that they get into the central nervous system; ensure that they are not destroyed by the body's own immune system; ensure that they grow to become the correct type of cell (for instance, to restore myelin); and to ensure that they do not overgrow or cause damage to the nervous system.

This approach to stem-cell therapy is being investigated in an open-label Phase I clinical trial announced in fall 2013. The design of this single-center trial includes enrolling 20 patients with progressive MS, and infusing doses of stem

cells harvested from the patients' own bone marrow directly into the cerebral spinal fluid (CSF). This is typically done via lumbar puncture, repeatedly over six months.

For more information about stem-cell research in MS, as well as references to these studies mentioned above, please see MSAA's 2015 *MS Research Update*. Please also watch for updates on MSAA's website at mymsaa.org. For current stem-cell studies, including those that are still recruiting, please visit clinicaltrials.gov and search for stem cells and MS. ♦

Phase III Study Data Added to Aubagio's Labeling

In November 2014, the United States Food and Drug Administration (FDA) approved adding the data from two Phase III studies to Aubagio®'s (teriflunomide) product label. These studies are the TOWER and TOPIC studies, which provide additional study results for Aubagio's efficacy and safety.

The addition of this study data informs medical professionals that this medication has been shown to (1) reduce the relative risk of sustained disability progression (along with reducing the annual relapse rate), as found in the Tower study, and (2) prevent or delay a second clinical attack (relapse), as seen in the TOPIC study, in individuals who were not yet diagnosed but experienced their first neurological symptoms suggestive of MS. Individuals in this latter group, who have not yet been diagnosed with MS but have experienced symptoms, are referred to as having clinically isolated syndrome (CIS). ♦

FOR MORE INFORMATION

on treatments for MS and other MS-related questions, individuals may contact MSAA's **Client Services Specialists** via email, phone, or our online chat feature. Please see the information below for contact details.

- Questions may be sent via email to MSquestions@mymsaa.org.
- MSAA's Client Services Specialists may also be reached by calling **(800) 532-7667, extension 154**. (Please note that MSAA's Specialists are available during normal business hours, 8:30 am to 5:00 pm ET, Monday through Friday.)
- MSAA offers an interactive one-on-one **chat feature at mymsaa.org/chat** that allows individuals to ask questions about MS while browsing MSAA's website.

MSAA Merges MRI Programs into the MRI Access Fund



For more than 12 years, MSAA has successfully operated two programs that provide magnetic resonance imaging (MRI) exams for individuals who need assistance to confirm a diagnosis of multiple sclerosis or track its disease progression. Through the expansion of new corporate support, MSAA has been able to combine the MRI Diagnostic and Institute programs into one service, as well as increase the number of clients served in 2015.

Although the name has changed to the MRI Access Fund, the program will operate in the same manner – assisting people who do not have adequate insurance coverage or the financial means necessary to acquire a cranial MRI. Supported by charitable contributions from EMD Serono and Pfizer, along with Genzyme, a Sanofi company, the MRI Access Fund will cover the remaining cost of a person's co-insurance balance or pay for an MRI through contracted imaging centers for qualified candidates.

Program applicants must meet income requirements, receive approval from MSAA prior to having an MRI (**no reimbursements will be given for previous MRIs**), and cannot exceed one MSAA-funded MRI exam within a 24-month period. If you have discussed with your physician the need for an MRI to aid in

diagnosing multiple sclerosis or evaluating disease progression and need assistance, please download the application at mysaa.org or contact MSAA at (800) 532-7667 to receive a copy in the mail.

This Summer, Don't Be Left Out in the Cold (Without Your Cooling Accessories!)

Once again, 'ole man winter really packed a powerful punch with record snowfalls, bitter wind chills, and prolonged arctic conditions. Although we're slowly thawing out from his deep freeze, we want you to imagine that it is summertime right now! Why? As temperatures begin to rise, so do requests for MSAA's Cooling Distribution Program. To avoid possible delays due to high demand, MSAA encourages you to apply now before the summer-cooling rush is upon us.

The MSAA Cooling Program offers a variety of ice-pack vests and accessories to help lessen heat sensitivity and allow people to spend time outdoors, enjoying family gatherings, gardening, and a variety of fun, summer activities. To help meet our client's needs, cooling products also include smaller,

lightweight vests that are easily hidden for discreet use and comfortable to wear, while at work or participating in your favorite exercise.

If you are interested in receiving cooling items and have not received products from MSAA within the past five years, please download the cooling application from mysaa.org or request a mailed copy by calling (800) 532-7667, extension 130.

MSAA's Library of Online Videos Reaches a Special Milestone

MSAA's online educational video library, known as Multiple Sclerosis Information (MSi), recently reached a significant milestone by generating more than 100,000 views since the program's inception in 2007! With 39 titles and growing, MSi offers a wide range of on-demand videos and archived webinars

designed to bring knowledge and empowerment right into the privacy and comfort of a person's home.

These award-winning videos feature top MS healthcare professionals providing valuable insights and updated information on the latest advances in MS, symptom-management techniques, exercise and wellness opportunities, and effective coping strategies. Other valuable program topics explore:

- the impact of MS on the family and personal relationships
- employment and disability issues
- the evolving world of health insurance coverage
- and many more "real-life" discussions to help people get the answers they need

We invite you to log onto mysaa.org/videos to watch an MSi program to learn more about multiple sclerosis and effective strategies to help you better manage and improve your life today. ♦

AWARD NEWS

We're pleased to announce that MSAA's video, "What You Need To Know About The Affordable Care Act," just won a 2015 Bronze Telly Award in the category of Health and Fitness!



Leaving a Legacy

MCAA has spent a great deal of time in the last year considering the footprint we make in the MS space. We know there are many more people out there affected by multiple sclerosis than we are currently reaching. We know there are many more for whom a cooling vest, a walker, or an expensive MRI could make the difference in improving their lives. It is our mission to be a leading resource for the entire MS community. This has led to some big plans and some big changes.

Among the many opportunities MCAA will be sharing in the upcoming months will be our renewed efforts in legacy giving. This type of giving is often called “planned giving” because of the careful consideration taken when making such a gift, or “deferred giving” because of the gift’s timing. I find I prefer the term “legacy giving,” defined very simply as the transfer and expression of one’s values through a gift to a charity. It helps each of us to answer the question, “What will you leave behind?”

Legacy gifts are easily made and can be as simple as naming a charity as the beneficiary of your savings, checking, or retirement account; or listing a charity in your will. Language for including MCAA in a will or trust can be found on our website, mymcaa.org. These simple gifts assure that the organizations you care about and support today will continue to fulfill their missions.

Other, more complex gifts – such as charitable annuities – can be an integral part of one’s financial strategy. These allow a donor

to significantly support an organization’s mission while continuing to draw an income that supports his or her own goals. MCAA recommends contacting your attorney or financial advisor for gifts of this nature.

Each of these types of legacy giving allows a meaningful way for individuals to express their values and transfer those values to the causes they care about most. These types of legacy giving also provide advantages for both the donor and the charity.

The benefits of legacy giving to an organization such as MCAA are vast. Numerous studies in the nonprofit arena have shown that legacy gifts assist organizations in achieving growth and sustainability. Our plans to expand our programs and provide even more MRIs, mobility aides, and educational programs, rely on enhancing and diversifying the support we receive.

Nearly everyone has the ability to make a legacy gift, and for many of us, it will be the largest gift we would ever be able to make. MCAA is excited to be launching this new effort... and providing those who value MCAA and our programs and services, the opportunity to share their values in a meaningful way. If you are interested in learning more about legacy giving, you may reach out to your attorney or financial advisor. You may also contact MCAA directly by emailing kgoodrich@mymcaa.org or calling (800) 532-7667, extension 101, so we may help you decide the best way to determine what you will leave behind. ♦

*Honors Two Vital People
 in the MS World*



Dr. Randall Schapiro,
MS Neurologist



Kristen Adams, *Emmy
 Award-Winning Producer*

This year's *Improving Lives* benefit dinner and program presentation is being held in Washington, DC on April 22, 2015. The benefit honors the accomplishments of MSAA champions in the MS community, while raising funds to support MSAA's vital programs and services. We thank both Dr. Schapiro and Mrs. Adams for their inspiration and important contributions to individuals with MS and their families!

THE
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The following thoughtful corporations, foundations and individuals have contributed generously to MSAA to improve the lives today for the entire MS community. Those providing gifts of \$10,000 or more during this fiscal year are shown in this listing.

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 The Foster Family Private Foundation Inc.
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 Stephen and Carole Jenkins
 Rita Kernen
 John and Cheryl Korth
 Barbara Kouris
 Virginia T. Dashiell Charitable Foundation
 Herbert I. Weisz

My Beautiful Life, with MS

By Tina Torizzo

I am, and always have been, one of those people who greet challenges with open arms. I actually don't just greet them; I try and hunt them down before they even greet me. My motto has always been, "God will only give you what you can handle." I have found out the hard way that this motto is way too true!



The author with her service dog, Crane

My story begins in May 2012. It was a beautiful spring day. I was running around with my kids, playing tag, climbing trees, rolling in the grass. Later that day, MS hit... like lightning out of a clear blue sky. I spent the next few months in and out of three different hospitals. I lost the ability to use my legs, arms, and hands. I could not write, feed myself, or even turn over in bed. I went through treatment after treatment with corticosteroids and then underwent plasmapheresis. Despite these treatments, I still lost vision in my right eye.

I remain on my disease-modifying therapy. For me, it's the only thing that would stop this terrible progression of symptoms. However, some symptoms did not fully remit following

this initial relapse. I was left with terrible balance, dizziness, fatigue (of course), and blindness in one eye. This blindness left me with no depth perception and therefore I have a difficult time seeing changes in terrain, such as steps, coming at me.

There was a day my husband dropped me off at a street-front store to do some shopping. Going in by myself was difficult enough, with the limited vision and balance, anxiety, and the feeling of being overwhelmed, which comes with new territory. So, I speedily headed out of the shop toward the car, not seeing the curb, and spilling out onto the busy street.

That is when I began my search for "something" something to help me

continue my life and my independence as I once knew. My husband and I always wanted to help train a seeing eye dog. Although, maybe now it could be the other way around and a dog could help me!



I researched many, many organizations and to my surprise, I found that people actually train dogs for mobility and balance. I had NO idea! I finally found an organization with all the right credentials and heart. It was ECAD, Educated Canines Assisting with Disabilities. I began the application process and met with them for a one-on-one interview. That was the point I actually got to try walking with a dog. It was amazing. I realized that I had to make this happen. The most difficult part was raising the money. I collected donations, held fundraisers, saved... and then waited... a year and a half.

Crane was born on Christmas Day 2012. She was born into Service Dog Training. The dogs get attention and training upon birth and until the day they are placed with a client. ECAD refers to each client's profile as they bring these dogs up and evaluate which dogs best have the skills to meet each client's needs. Crane was a special dog because she had to be proficient at all of her "assist dog skills" and also be my eyes. She had to be able to concentrate while I dealt with my three kids and busy lifestyle. She had to be a dog that also welcomed challenge. Crane seemed to fit the bill!

Once ECAD thought they had a potential match, they called me in for Team Training. During Team Training, the client lives at the

ECAD facility in Dobbs Ferry, New York, for two weeks and undergoes intensive training with the dogs. The goal is that by day four, you will be partnered with what will be "your" dog.

Crane claimed me the first day, the first second she saw me! She was mine. She has been taught things such as to open doors, turn on and off lights, help with the

laundry, get my shoes, retrieve things off the ground, and more. She is able to brace and balance me with a harness on her vest and she guides as well. Stairs, ice, holes, hills, etc., she's got me. In busy places, I attach my kids' color-coded leashes onto her vest and I know they are safe, because Crane is in charge.

I might have MS. It probably will get worse. However, with Crane, I feel like I can still conquer the world. I am optimistic about my condition and even began a blog to help others going through something similar, at www.mybeautifullifewithms.com. I go out alone, or with just my three kids, and to everyone else in the world, I am not disabled. I just look like a woman with a dog! ♦

Learn More About MSAA!

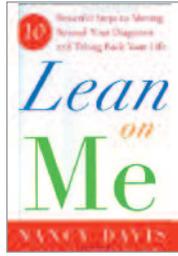


To order your free copy of *Improving Lives Today*, please visit mysaa.org/publications or call (800) 532-7667.

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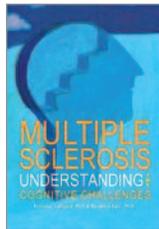
Written by Nancy Davis,
of Race to Erase MS
Published by Fireside Books
MSAA Book #419



When author Nancy Davis was diagnosed with MS at age 33, she decided to take control through education, a healthy lifestyle, a positive outlook, and becoming her own health advocate. In her book, she tells her story and offers a step-by-step guide to empower others. Through her work with Race to Erase MS, Nancy is the founder of Center Without Walls, a national medical research foundation, and has assisted with raising millions of dollars for MS research.

Multiple Sclerosis: Understanding the Cognitive Challenges

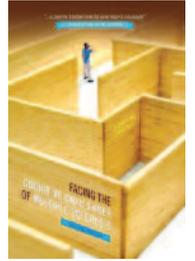
Written by Nicholas LaRocca, PhD
and Rosalind Kalb, PhD
Published by Demos Medical Publishing
MSAA Book #325



This valuable resource provides an in-depth look at how cognition may be affected by MS, the social and emotional impact of cognitive issues, as well as research, assessment, and strategies for treating this often-challenging symptom. Written by two clinical psychologists, this insightful book emphasizes that people with cognitive issues are not alone, and that many others have found ways to manage and cope with this symptom.

Facing the Cognitive Challenges of Multiple Sclerosis, Second edition

Written by Jeffrey N. Gingold
Published by Demos Health
MSAA Book #404



In this book, the author explains how he came to find that he had MS and how he tried to conceal and cope with cognitive and other issues. Mr. Gingold talks first-hand about unexpectedly encountering a lapse in memory, an inability to recall words, or finding himself lost on a familiar road. He includes details about the other symptoms, consulting doctors, undergoing tests, taking medication, and eventually retiring from his active law practice. This resource is well written and entertaining, offering valuable tips at the end of each chapter.

MSAA's Lending Library

To borrow books featured in this column or any other book in MSAA's Lending Library, please visit mymsaa.org/library to view a list of books available and to complete a form. When ordering a book, please reference the book number listed. Readers may also call MSAA at (800) 532-7667 for more information. MSAA and its clients greatly appreciate any donations made to help build the Lending Library. Please send your book donations to: MSAA Lending Library, 706 Haddonfield Road, Cherry Hill, NJ 08002.



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Art Showcase



and the inaugural
Four Seasons Showcase

CELEBRATING THE WORK OF ARTISTS AFFECTED BY MULTIPLE SCLEROSIS

MSAA's 2015 Art Showcase includes various themes and features a number of different styles. Artwork highlighted in the Four Seasons Showcase depicts a specific season or holiday.

In 2014, we received many wonderful submissions from individuals across the country. We are delighted to now share their work and stories with you!

We invite you to view the complete online gallery of artwork from participants in MSAA's 2015 Art Showcase. Please visit mymsaa.org/artshowcase2015



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