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RELAPSINGImage: StructureImage: Structure<

Diving Into Aquatic Therapy p.16

WELCOME to HealthCentral's guide to Relapsing Multiple Sclerosis. In these pages, you'll learn about current research, how to make the most of every doctor visit, the latest treatments, and more. For additional tips and information on MS, go to healthcentral.com/msguide.



WHAT IS **MYOCLONUS?**

People with MS (and other neurological disorders) are more susceptible to myoclonus—a sudden, involuntary jerking of muscles. Myoclonus varies in frequency and intensity and, in some people, occurs in response to loud noises or other unexpected stimuli. If severe, myoclonus can be treated with medication: Clonazepam (Klonopin) is commonly prescribed, but other drugs may be used. While this is a lesser-known symptom of MS, myoclonus can affect anyone: Hiccups are an example.

Research Bulletin: A recent study, funded in part by the National Multiple Sclerosis Society, found a connection between obesity and MS progression. Researchers compared people with MS who were overweight or obese to MS patients who were not. The former had higher levels of blood lipids called ceramides, which caused the body to produce more monocytes (a type of white blood cell that has been linked to damaged neurons in the brains of people with MS), and after two years, had worse disease activity.

Number of MS studies recruiting on clinicaltrials.gov

5 Great Benefits of Functional Fitness

Functional fitness programs are key if you're living with MS because they prepare your body for real-life situations and activities. The National Multiple Sclerosis Society breaks down functional fitness into five components. Make sure that your exercise routines touch on each of the following areas.

1 Strength and Endurance: Strength training can combat weakness and help prevent injury by building muscle, increasing bone density, and improving flexibility and balance.

Flexibility and Range of Motion: Flexibility exercises Can help increase your range of motion, enhance joint integrity, prevent injury, and alleviate stress.

Cardiovascular Exercise: Good for the heart, cardio also A helps beat fatigue and build endurance.

Relaxation and Body Awareness: Relaxation exercises 4 such as yoga and tai chi can help relieve stress and lessen spasticity. Awareness of how your body moves will make it easier for you to spot problem areas to work on.

Balance and Coordination: Routines targeting these areas can improve poor posture and body alignment common in people with MS.

MS Myths & Facts

Myth: MS doesn't cause pain.

Fact: In the past, some doctors believed that MS was painless. We now know that up to two-thirds of people with MS experience pain. Primary pain results from damaged or inflamed nerves directly due to MS. Secondary pain can be caused by treatments or changes to your body as a result of MS.

Myth: Lhermitte's sign causes permanent brain damage.

Fact: This electrical-shock sensation, often triggered when the neck is flexed forward, affects about a third of people with MS. While it may be bothersome, it typically requires no treatment and is not a sign of brain damage or MS progression.



What are the most common triggers for flare-ups?

We don't really know what will bring on a flare-up, or relapse. There are certain times when they are more common—for example, during the postpartum period in the first three months after delivery, so clearly there's something about hormones that leads to increased disease activity. Also, we know that an infection or a flu-like illness can lead to immune activation that can bring on an attack.

Researchers have tried to determine whether increased stress can set off an MS relapse, but the findings aren't consistent. We do know that your coping abilities can affect your immune system, so at the individual level, how you handle stress matters.

Fears about losing control are a big issue with MS. How do you recommend people address that? Everyone should eat well, exercise regularly, get enough sleep, and take good care of their health—it's even more important with MS. If you can take control by doing more taxing or challenging tasks in the morning when energy and focus are higher, that will help you. Trying to structure your day so you don't feel you're at the whim of things can make a difference, too.

Does MS shorten life expectancy?

It used to, but people with MS are doing a lot better now. We have very effective therapies that control relapses and are associated with better long-term outcomes, better







overall neurologic function, and less brain injury. As a result, we're more capable of preventing deconditioning and pneumonia and better equipped at keeping people well oxygenated and hydrated, which improves health over time.

What do you wish patients with MS asked you but usually don't?

They don't tend to ask me why I'm recommending a medication or why they should take it. Sometimes people don't understand that the medications we use—the disease-modifying therapies and the symptomatic treatments—are not the same. If you're on a medication that modifies the disease course, whether it's an intravenous infusion or a pill, it's important to recognize that that drug is not going to make a difference in your fatigue, pain, or other symptoms. Rather, these drugs prevent the inflammation and disease activity that injure the nervous system.

TOP:



ASK THE EXPERT: LAUREN B. KRUPP, M.D.

What is your hope for the future of MS treatment?

In the future. I think the condition will be so well controlled that you won't need to concern yourself so much with multiple sclerosis. In some ways, we're almost there. If people catch MS early and get the right medications, they can do really well. Additionally, I would like to see better opportunities for repairing the damage that has already happened as a result of MS. Once we're able to enhance repair-with remyelination (the generation of new myelin sheaths in the central nervous system), for example-we will be in a very different place. I think we'll get there. 🔳



LAUREN B. KRUPP, M.D.,

is a professor of neurology and director of the Multiple Sclerosis Comprehensive Care Center at NYU Langone Health in New York City.



Nearly one million people in the United States are living with multiple sclerosis.

ultiple sclerosis (MS) is a chronic and progressive disease of the central nervous system. While the severity, symptoms, and course of the disease vary, an MS diagnosis is not the blow that it used to be. Most people with MS are diagnosed between ages 20 and 50, and the disease is significantly more prevalent in women than men. The prime cause remains a mystery, but risk factors may include ethnicity, family history, exposure to certain viruses, and low levels of vitamin D.

In MS, the immune system mistakenly attacks myelin, a fatty substance that insulates nerves and helps them communicate. Over time, this can lead to scarring (known as sclerosis or lesions) and hardening of nerve tissue in the spinal cord. brain, and eyes. These lesions can cause pain and weakness in the extremities, vision impairment, and

cognitive problems, among other issues. Because the exact locations of the damage vary from person to person, so do the signs and symptoms that people experience.

4 Types of MS

Four forms of this disease have been identified: clinically isolated syndrome (CIS); relapsing-remitting MS (RRMS); primary-progressive MS (PPMS); and secondary-progressive MS (SPMS).

A person with CIS experiences a first episode of neurological symptoms lasting a minimum of 24 hours. The event is caused by either inflammation or damage to myelin in the central nervous system. Some people who experience CIS go on to develop MS of one form or another. and some don't.

About 85 percent of people with MS are initially diagnosed with RRMS. Here are some factors that

distinguish RRMS from other forms of the disease:

- People with RRMS tend to have more brain lesions, as seen on magnetic resonance imaging (MRI) scans, and these lesions contain more inflammatory cells. In contrast, people with PPMS tend to have more lesions on the spinal cord than in the brain. and fewer inflammatory cells are present.
- RRMS is generally diagnosed earlier in life than other forms of MS.
- Most people with RRMS eventually develop SPMS, a form of the illness that involves a steady and sustained worsening of symptoms over time. The transition to SPMS generally occurs after a person has had RRMS for a decade or longer.

RRMS Symptoms

In the early stages of this condition, people may experience blurred or double vision, muscle weakness, stiffness, spasms, tingling and



1. PLAN YOUR DAY. Fatique plagues many people in their later years; it's also a common symptom of MS. Add these together, and it's clearly important to conserve your energy for what matters most. Decide what things you'd like to get done in a given day, make a plan, and take advantage of your higher-energy times for accomplishing them.

2. GET GOOD SLEEP. There are many causes of sleep problems in people with MS, from frequent napping in the day due to MS-related fatique to havoc in certain

numbness in the limbs, problems with coordination and balance, and fatigue. Many people with RRMS notice that certain activities or situations, such as taking a hot bath or being under a lot of stress, seem to trigger a flare-up—that is, a period of intensifying symptoms (also commonly referred to as a relapse or an exacerbation).

If damage to the central nervous system progresses in a person with RRMS, other health issues can develop. These can range from depression and various mood changes to difficulties with memory and concentration, urinary urgency and frequency (having to use the toilet very often), bowel problems such as constipation, and sexual difficulties.

The ways in which people experience RRMS vary widely. Some individuals have flare-ups, which can last anywhere from days to months before easing up, while others notice a gradual but steady increase in physical



SMART MOVES AS YOU GET OLDER

Life expectancy for people with MS is about the same as it is for the rest of the population, though there's a greater likelihood of physical disabilities developing. Healthy living with attention to minimizing stress and exercising regularly are key to aging well with MS. Also:

neurotransmitters involved in slumber. And it's common for sleep troubles to increase with normal aging. Tackle these issues by actively addressing MS symptoms that may be interfering with sleep, and visit the National Multiple Sclerosis Society's website (nationalmssociety.org) for more suggestions.

3. PRIORITIZE SOCIALIZING.

Keeping up ties with friends and family, and being engaged and stimulated, can help you stay alert and upbeat. This is true for all people as they age, but perhaps particularly so for

handling health setbacks.

and cognitive decline over time. Still others live for years with only small reminders that they have the disease.

There's no way to predict what course the illness will take in any given individual, but with the appropriate therapy, the majority of people with MS do not become disabled, explains Brian R. Apatoff, M.D., Ph.D., associate professor of neurology and neuroscience at Weill Cornell Medical College and director of the Multiple Sclerosis Institute in New York City. "We have some amazing therapies."

Reasons to Be Hopeful

While there is no cure for MS, the outlook is dramatically better than it used to be for people with the disease, says Dr. Apatoff. "Research in MS is one of the most active areas in the field of neurology, with several new therapies in the pipeline," he remarks. "MS is one of neurology's bright and shining areas of investigation."

For more information on multiple sclerosis, go to **HealthCentral.com/msguide**.

those with MS who are prone to feeling isolated or blue. or have trouble getting around. Find a regular card game or book club, or set up weekly phone calls with a faraway friend. Friendships also make a difference when it comes to

4. SEE YOUR DOCTOR REGU-

LARLY. It's important to stay closely connected to your healthcare team so that you can quickly spot and address any health issues that might slow you down unnecessarily or somehow add to the normal challenges of aging

Consistent care can give you an edge for aging well.

5. ASK FOR HELP, ACCEPT

HELP. Everyone can use a helping hand as the years go by; when you have MS, assistance can be even more valuable. Take advantage of help in all of the ways it's offered, whether it's support ascending the stairs or help with laundry.

To connect to services in your area, check out the Eldercare Locator (eldercare.acl.gov; 800-677-1116) and the Aging Life Care Association's website (aginglifecare.org).

Doctor Discussion Guide: RELAPSING MULTIPLE SCLEROSIS

Receiving the right care and monitoring your symptoms can make a world of difference when managing your multiple sclerosis and quality of life. Take an active role in your care, ask your physician questions, and bring along your caregiver for support. Advocating for yourself is key! Complete the guide below to further your understanding of symptoms and treatments — and to attain a partnership with your doctor.

On a scale of 1 to 5, since my last visit my symptoms have: *(circle on scale below)*



Do you think the symptoms I'm having indicate a relapse?

What could trigger a relapse? How can exacerbations be treated?

What disease-modifying therapies (DMTs) are available? What are the benefits and risks?

How can we work together to achieve the best results?

This is how I would best describe my symptoms:

- (check all that apply)
- Light-sensitivity
- Trouble seeing
- 🗌 Eye pain
- Difficulty swallowing
- Muscle weakness
- 🗌 Stiffness
- Balance and coordination difficulties
- □ Trouble concentrating
- \Box Memory deterioration
- Difficulty sleeping
- □ Slurred speech
- 🗌 Fatigue
- Urinary and/or bowel issues
- Sexual difficulties
- 🗆 Pain
- Tremors (shaking)
- Depression

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The right care can make a world of difference with MS.

eople with MS often see a team of healthcare professionals: a neurologist (one who specializes in MS, if at all possible), social worker, psychologist, neuropsychologist, nutritionist, and physical and occupational therapists, among others.

The goal of treatment is to slow the progression of the disease or halt it entirely. But measuring this can be complicated, as MS symptoms can fluctuate from day to day and visit to visit. That's one reason your physician will probably want to see you every three to six months in the first one or two years after your diagnosis. After that, your visits may occur anywhere from every six months to annually. Be sure to follow the recommended schedule of visits so that your doctor can monitor your health over time, conduct necessary tests, and adjust treatments as needed.

At each appointment, ask for a printed or emailed copy of any instructions your doctor gives you, as well as for any prescription refills you

1. PREPARE FOR YOUR
DOCTOR VISITS. Keep a2. Monosciencerunning log to track changes
in your health (positive and
negative) between appoint-
ments. Doing so will make it
easier to recognize disease
progression. Bring this log-
as well as a list of questions
for your doctor—to your
appointments.2. Monoscience
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2. MONITOR YOUR SYMP-
TOMS. New or changing3toms. New or changingtsymptoms may indicate an
exacerbation. The most com-
mon are vision issues, vertigo,
weakness or numbness in the
limbs, balance and coordina-
tion problems, falling, trouble
walking, speech changes,
memory loss, fatigue, and
s
bladder or bowel problems.3

3. CALL THE DOCTOR. If you think you might be having an exacerbation, contact your neurologist. Sometimes the best way to stop a symptom is an immediate course of therapy. At other times, you may just need to ride it out. Together, you and your physician can determine the best approach.

HealthCentral.com/msguide

MSD2

OFFICE VISIT

need; you should also schedule your next visit. If you experience troubling symptoms between scheduled visits, make another appointment. Taking care of symptoms promptly can make a dramatic difference in your disease progression.

Monitoring Your MS

Once you are diagnosed with MS, you will need regular tests to check on your response to treatment and to determine whether your disease is progressing. Tests may include:

Magnetic resonance imaging (MRI). This technology produces highly detailed images of your body. With an MRI of the brain and spinal cord, doctors can spot lesions characteristic of MS, as well as other changes.

Neurological exam. Your physician will check your reflexes, coordination, gait, and balance.

■ Vision. It's not uncommon for people with MS to experience blurred vision or double vision, so your doctor will look for signs of damage to the optic nerve.

Other senses. Your doctor may test your ability to feel pain and other sensations, along with your senses of smell, taste, and hearing.

■ Cognitive function. MS can affect the way your brain works, so you may have tests that focus on speech processing, working memory, reasoning and planning, visual perception, and language. ■

4 WAYS TO STAY ON TRACK

4. SEE AN MS SPECIALIST.

Bianca Weinstock-Guttman, M.D., director of the Jacobs Multiple Sclerosis Center for Treatment and Research at the University at Buffalo, advises consulting the National MS Society (**nationalmssociety.org**) or the Consortium of Multiple Sclerosis Centers (**mscare.org**) to find one.



For avid skier Leigh Kaplan, challenging herself is empoweringespecially on a mountaintop.

o see Leigh Kaplan powering through her job as a physical therapist or skiing the powdery slopes of Breckenridge, Colorado, you'd never guess the 30-year-old has multiple sclerosis.

"Nobody would ever choose to have MS," says Kaplan, who lives in New York City. "But I really like the life I'm living now more than my life five years ago. I don't know that I'd have gotten here as fast as I did had MS not happened to me. It truly puts your life in perspective and focuses you."

Kaplan was in the last semester of her doctoral program in physical therapy in 2013 when the vision in her left eye became blurry. A few weeks later, she noticed reduced sensitivity on her right thigh when she was shaving her legs in the shower. She decided to see an ophthalmologist, which led

to a visit with a retinal specialist, and finally a neuro-ophthalmologist, who suspected she might have MS.

MRI (magnetic resonance imaging) scans showed multiple lesions on her spine, so Kaplan was given steroids and hospitalized while doctors confirmed the diagnosis. She wasn't put on an MS drug immediately, but when she started having blurry vision in her other eye a couple of weeks later, she was put on another course of steroids and prescribed a disease-modifying therapy, administered via monthly infusion. She hasn't had an exacerbation since then.

Managing Everyday Symptoms

Still, Kaplan is reminded of her MS every day. Her No. 1 symptom is fatigue, which she has learned to

manage over time. "MS fatigue is a lot different than ordinary fatigue. It's stop-you-in-your tracks, you-need-to-take-a-break type of fatigue," she says. "However, the longer you live with it, the easier it becomes to manage. You know your body a lot better, so you're not trying to push through in a way that you can't push through."

She's found that taking minibreaks makes a big difference. "Even if it's just 10 minutes, you sit downmaybe in a dark room—you relax, and then you start," Kaplan says. Meditation and yoga have helped.

She has also eliminated dairy and gluten products from her diet and tries to avoid processed foods. "For me, cutting all of those things really fights fatigue-and contributes to a healthier life," she says.

These measures helped her finish her degree and build up her work schedule. "When I was first diagnosed, it was like, 'How am I going to do this job?" she says. "I want to help people maximize their function, and now I'm in these shoes."

She experimented with different strategies to maximize her potential at work. "This was my dream career, and I wanted to keep pursuing it," she says. "I didn't want to just give up. Over time I've built up the number of days I'm working. I'm really just like any other therapist now, even though I have my days. But so does everybody."

Kaplan also has bladder issues, requiring her to urinate frequently, and she deals with vertigo, especially when the weather is warm. She also experiences some pain on the right side of her body.

She was afraid she might not be as athletic as she had been before her MS diagnosis. She played basketball in college and loves to ski. The disease hasn't changed that. "When you're living with something you feel like you can't control, there's something about standing on a mountaintop looking down and realizing, 'OK, you're taking on this huge challenge

and succeeding," she says. "You just feel invincible."

The MS Dating Game

Single when she was diagnosed, Kaplan also worried about her prospects for dating. She didn't go out with anyone for two years—and she's glad. "I wanted to just get really comfortable living with this disease instead of putting a burden on someone else," she says. "I didn't know how to live with it yet. I also got confident with telling my story, so that when you're on that fourth or fifth date and you're telling somebody about what's going on with you, it doesn't come from a place of embarrassment or feeling uncomfortable: 'This is who I am. Bad things happen to people. Take it or leave it."

By the time she met Daniel Krauss, the man who would become her husband, she was comfortable in her skin. Their relationship took off. "I got extremely lucky and met the love of my life," Kaplan says. "And he's so supportive and understanding about this disease." The couple married in October 2018 on a mountaintop in upstate New York.

A Quarter Million Raised for MS Research

Almost from the beginning, Kaplan felt the need to contribute to the MS cause and raise awareness of the disease. Since 2015, she has captained a team in the annual Climb to the Top NYC fund-raising event for the National Multiple Sclerosis Society, which involves ascending 66 flights of stairs to the top of Rockefeller Center. The team, dubbed Team Kapniss—a nod to Katniss, the fearless heroine of the Hunger Games series—has raised more than \$250,000 for MS research.

"It's one of the best life-changing things I ever did for myself," Kaplan says. "When you're diagnosed, all you're thinking is, 'Why me?' Then





Kaplan married Daniel Krauss on top of a mountain in 2018.

you see how many people are impacted and that participating in such a big thing can make a change in other people's lives."

She likes to reassure people who have recently been diagnosed with MS. "I really wish that I could have talked to somebody like me-now five years out—rather than being left with the internet. where the outlook can seem verv dark." she says. "Truthfully, MS is so different now than it was even 10 years ago. Getting firsthand accounts of people who are living and thriving despite the challenges of the disease can be very empowering."

Her physician, Brian R. Apatoff, M.D., Ph.D., director of the Multiple Sclerosis Institute in New York City, says, "Leigh has not let her diagnosis slow her down, maintaining her wonderful positive approach to work and her personal life. As a healthcare professional, she is a great role model!" Kaplan's message to others?

"Don't let MS stop you."

For more information on multiple sclerosis, go to HealthCentral.com/msguide.



Your Rx Options

Multiple sclerosis treatment is one of the most dynamic areas of medicine.

hirty years ago, there was not a single approved drug for treating MS. Today, there are 17 medications for relapsing-remitting MS (RRMS), including one also approved for primary-progressive MS (PPMS) and several approved for secondaryprogressive MS (SPMS).

Nonetheless, MS can be challenging to treat. The nature of your illness, how severe it is, and your specific symptoms all come into play when determining which therapy is best for you. Disease-modifying therapies (DMTs) focus on slowing the progression of the disease and changing its course. While none can cure MS, they can reduce the accumulation of lesions in the brain and spinal cord, as well as lessen the frequency and severity of attacks. They also play a role in reducing the progression of disability. DMTs fall into three categories: injectable medications, those that are given via intravenous (IV) infusion, and those that are taken orally (see chart).

Other drugs that may be used are geared toward controlling symptoms

such as fatigue, depression, muscle stiffness and spasms, and bladder and bowel problems. Additionally, there are a few nondrug therapies that can help take care of some symptoms.

Medication decisions come down to evaluating the balance between a drug's benefits and risks. "We may choose drugs that have fewer side effects but take longer to begin working in a patient who has a very slowly worsening disease," explains Robert Glenn Smith, M.D., Ph.D., a neurologist at Houston Methodist Hospital in Texas. "Or we may choose a drug that's a lot more aggressive in its beneficial effects, but may have more side effects, for somebody with more active disease."

With so many different treatment options available for MS, there may be some degree of trial and error involved in the process. Try not to get discouraged if it takes a few attempts before finding what works best. Together, you and your doctor will come up with the right treatment plan for you.

DMT TYPES



INJECTABLES: The injectable DMTs are interferon beta-1a (Avonex, Rebif), interferon beta-1b

(Betaseron, Extavia), glatiramer acetate (Copaxone, Glatopa), and peginterferon beta-1a (Plegridy). "The interferons and glatiramer acetate are overall the safest," says Vijayshree Yadav, M.D., associate professor of neurology at Oregon Health & Science University School of Medicine in Portland, but they may not be as effective as some of the newer drugs. The most common side effects of interferons include flu-like symptoms and irritation around the injection site.



INFUSIONS: The DMTs administered via IV infusion are alemtuzumab (Lemtrada), mitox-

antrone (also approved for SPMS), natalizumab (Tysabri), and ocrelizumab (Ocrevus); the last of these is approved to treat both RRMS and PPMS. Depending on the medication, infusion time can range from as little as five minutes to several hours, and infusions are repeated anywhere from daily to yearly for varying periods of time. Side effects vary by drug, so be sure to ask your doctor about those.



ORAL MEDS: DMTs taken in pill form include teriflunomide (Aubagio), fingolimod (Gilenya),

and dimethyl fumarate (Tecfidera). Two new drugs in this category, cladribine (Mavenclad) and siponimod (Mayzent), are approved to treat active SPMS, as well as RRMS. Oral meds have the advantage of convenience, but all MS drugs have side effects and risks, so talk to your doctor about the best option for you. ■ Need to Talk? The Multiple Sclerosis Association of America (MSAA) has a free helpline (800-532-7667, ext. 154), providing support and referrals. Not up for a phone conversation? Try the online chat feature (mymsaa.org/chat).

■ **MSAA MRI Access Fund** Need an MS-related MRI but don't have medical insurance or can't afford insurance costs? Apply to this program; you may be eligible to have some or all of your MRI costs covered (mymsaa.org/msaa-help/mri).

MS Fit Facts

Move your body to calm your mind and gain energy.

Exercise can be a valuable component of managing MS symptoms. If you haven't found the right exercise program for you, check out the National Multiple Sclerosis Society's website (nationalmssociety.org), which has many exerciserelated links that can help. Here are a few examples of the benefits that certain types of exercise offer:

Yoga: Boosts physical and emotional well-being.
Pilates: Strengthens core muscles and improves overall physical stability.

• Aerobic exercise (e.g., walking or cycling): Enhances mood and has positive effects on mental and physical health.



Getting Started With Aquatic Therapy

Aquatic therapy is an exercise superfood for people with MS, because it enhances flexibility, cardiovascular fitness, muscle strength, and mobility function, and provides psychological benefits. There are programs for all levels of fitness, and a cool pool can be soothing for those sensitive to heat. The MSAA has a few tips on getting started:

CHECK WITH YOUR DOCTOR. Start by talking to your healthcare team about how your MS might affect your ability to exercise in water.

SET GOOD GOALS. Identify some realistic goals—such as better balance, arm strength, or stability—to help pick the right program.

FIND THE RIGHT POOL. To enroll in appropriate classes, check with nearby gyms and facilities such as the YMCA to see what they offer. You can also contact the MSAA for assistance.

INTRODUCE YOURSELF TO THE TEACHER. Let the instructor know you have MS and tell them your fitness goals before you start your sessions.

5 ENJOY YOURSELF! Fun is the secret to staying motivated. If it's not fun, try to find another class.

For more tools and tips, go to **HealthCentral.com/msguide**.

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