

InforMS

Spring 2020
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Rocky Mountain
Multiple Sclerosis Center

PAIN

Exploring one of the most common and often misunderstood symptoms of MS.

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MS **AWARENESS MONTH**
ROCKY MOUNTAIN MS CENTER
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Laura S., living with relapsing MS

Say **yes** to TECFIDERA—a pill that can **cut MS relapses**.

TECFIDERA is a pill shown to **work against relapsing multiple sclerosis (MS)** in **3 important ways**. TECFIDERA can:



What is TECFIDERA® (dimethyl fumarate)?

- TECFIDERA is a prescription medicine used to treat relapsing forms of multiple sclerosis (MS), to include clinically isolated syndrome, relapsing-remitting disease, and active secondary progressive disease, in adults
- It is not known if TECFIDERA is safe and effective in children under 18 years of age

Important Safety Information

Who should not take TECFIDERA?

- Do not use TECFIDERA if you have had an allergic reaction (such as welts, hives, swelling of the face, lips, mouth or tongue, or difficulty breathing) to TECFIDERA or any of its ingredients

Before taking and while you take TECFIDERA, tell your healthcare provider if you have or have had:

- low white blood cell counts or an infection
- any other medical conditions

Tell your healthcare provider if you are:

- pregnant or plan to become pregnant. It is not known if TECFIDERA will harm your unborn baby
 - If you become pregnant while taking TECFIDERA, talk to your healthcare provider about enrolling in the TECFIDERA Pregnancy Registry. You can enroll in this registry by calling 1-866-810-1462 or visiting www.tecfiderapregnancyregistry.com. The purpose of this registry is to monitor the health of you and your baby
- breastfeeding or plan to breastfeed. It is not known if TECFIDERA passes into your breast milk. You and your healthcare provider should decide if you will take TECFIDERA or breastfeed
- taking prescription or over-the-counter medicines, vitamins, or herbal supplements

What are the possible side effects of TECFIDERA?

TECFIDERA may cause serious side effects, including:

- **allergic reaction** (such as welts, hives, swelling of the face, lips, mouth or tongue, or difficulty breathing)

opens up possibilities

- **PML** a rare brain infection that usually leads to death or severe disability
- **decreases in your white blood cell count** Your healthcare provider should do a blood test before you start treatment with TECFIDERA and while on therapy
- **liver problems.** Your healthcare provider should do blood tests to check your liver function before you start taking TECFIDERA and during treatment if needed. Tell your healthcare provider right away if you get any of these symptoms of a liver problem during treatment
 - severe tiredness
 - loss of appetite
 - pain on the right side of your stomach
 - have dark or brown (tea color) urine
 - yellowing of your skin or the white part of your eyes
- **herpes zoster infections (shingles)**, including central nervous system infections
- **other serious infections**

The most common side effects of TECFIDERA include:

- flushing, redness, itching, or rash
- nausea, vomiting, diarrhea, stomach pain, or indigestion
- Flushing and stomach problems are the most common reactions, especially at the start of therapy, and may decrease over time. Taking TECFIDERA with food may help reduce flushing. Call your healthcare provider if you have any of these symptoms and they bother you or do not go away. Ask your healthcare provider if taking aspirin before taking TECFIDERA may reduce flushing

These are not all the possible side effects of TECFIDERA. Call your healthcare provider for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088. **For more information go to dailymed.nlm.nih.gov.**

Please see full Prescribing Information, including Patient Information.

This information does not take the place of talking with your healthcare provider about your medical condition or your treatment.

Say **yes** to finding support.

You may be eligible for the **Biogen Copay Program**.

Are you ready to say yes to the possibility of fewer relapses?
Visit yestoTEC.com or call **1-844-TalkTec (1-844-825-5832)**.

*Based on number of prescriptions from IMS NPA™ Weekly Data (September 27, 2013 – December 27, 2019).

 **TECFIDERA**[®]
(dimethyl fumarate) delayed-release capsules 240 mg



Patient Information
TECFIDERA® (tek" fi de' rah)
(dimethyl fumarate) delayed-release capsules

What is TECFIDERA?

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- It is not known if TECFIDERA is safe and effective in children under 18 years of age

Who should not take TECFIDERA?

- Do not use TECFIDERA if you have had an allergic reaction (such as welts, hives, swelling of the face, lips, mouth or tongue, or difficulty breathing) to TECFIDERA or any of its ingredients. See below for a complete list of ingredients.

Before taking and while you take TECFIDERA, tell your doctor if you have or have had:

- low white blood cell counts or an infection
- any other medical conditions

Tell your doctor if you are:

- pregnant or plan to become pregnant. It is not known if TECFIDERA will harm your unborn baby.
 - If you become pregnant while taking TECFIDERA, talk to your doctor about enrolling in the TECFIDERA Pregnancy Registry. You can enroll in this registry by calling 1-866-810-1462 or visiting www.tecfiderapregnancyregistry.com. The purpose of this registry is to monitor the health of you and your baby.
- breastfeeding or plan to breastfeed. It is not known if TECFIDERA passes into your breast milk. You and your doctor should decide if you will take TECFIDERA or breastfeed.
- taking prescription or over-the-counter medicines, vitamins, or herbal supplements

How should I take TECFIDERA?

- Take TECFIDERA exactly as your doctor tells you to take it
- The recommended starting dose is one 120 mg capsule taken by mouth 2 times a day for 7 days
- The recommended dose after 7 days is one 240 mg capsule taken by mouth 2 times a day
- TECFIDERA can be taken with or without food
- Swallow TECFIDERA whole. Do not crush, chew, or sprinkle capsule contents on food.
- Protect TECFIDERA from light. You can do this by storing the capsules in their original container.
- If you take too much TECFIDERA, call your doctor or go to the nearest hospital emergency room right away.

What are the possible side effects of TECFIDERA?

TECFIDERA may cause serious side effects including:

- **allergic reaction** (such as welts, hives, swelling of the face, lips, mouth or tongue, or difficulty breathing)
- **PML** a rare brain infection that usually leads to death or severe disability
- **decreases in your white blood cell count** Your doctor should do a blood test before you start treatment with TECFIDERA and while on therapy.
- **liver problems.** Your doctor should do blood tests to check your liver function before you start taking TECFIDERA and during treatment if needed. Tell your doctor right away if you get any of these symptoms of a liver problem during treatment.
 - severe tiredness
 - loss of appetite
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General Information about the safe and effective use of TECFIDERA

- Medicines are sometimes prescribed for purposes other than those listed in this Patient Information. Do not use TECFIDERA for a condition for which it was not prescribed. Do not give TECFIDERA to other people, even if they have the same symptoms that you have. It may harm them.
- If you would like more information, talk to your doctor or pharmacist. You can ask your doctor or pharmacist for information about TECFIDERA that is written for healthcare professionals.

What are the ingredients in TECFIDERA?

Active ingredient: dimethyl fumarate

Inactive ingredients: microcrystalline cellulose, silicified microcrystalline cellulose, croscarmellose sodium, talc, silica colloidal silicon dioxide, magnesium stearate, triethyl citrate, methacrylic acid copolymer - Type A, methacrylic acid copolymer dispersion, simethicone (30% emulsion), sodium lauryl sulphate, and polysorbate 80.

Capsule Shell: gelatin, titanium dioxide, FD&C blue 1; brilliant blue FCF, yellow iron oxide and black iron oxide.

Manufactured for: Biogen Inc., Cambridge, MA 02142, www.TECFIDERA.com or call 1-800-456-2255

ROCKY MOUNTAIN MS CENTER

— the answers begin here —

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RMMSC Mission Statement

To improve the quality of life of individuals
and their families living with MS and
related neurological diseases through care,
support, education and research.

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From the CEO



Welcome to the first issue of InforMS
Magazine for 2020!

You should be receiving this issue in
the midst of **MS Awareness Month**,
which we celebrate every March
as a way to raise awareness in our
communities about the disease that
affects so many of our lives. MS
Awareness Month is an opportunity
to help grow understanding of MS
with friends, neighbors, co-workers
and others who may not always have
a good idea of what it means to live
with MS.

In this issue, we've included a brief
guide to some of the most basic
elements of multiple sclerosis (see
page 20). We hope this is something
you'll be able to use to help educate
people in your life that may know you
have MS, but not really "get" what that
means to you every day.

We've also included some ways you
can get involved in MS Awareness
Month, by supporting the MS Center
in some new ways (see page 21).
Most notably, we've relaunched
our monthly giving program as a
convenient and sustainable way for
you to support the RMMSC's work at
any level that's right for you. Monthly
donors are our "Friends of the MS
Center," and we hope you'll consider
joining us!

EDUCATION SUMMIT

I'd also like to take a moment to invite
you to our upcoming Education
Summit, being held on the CU
Anschutz Medical Campus on
Saturday, April 18. If you've never
attended before, our Education
Summits are a truly unique chance
for you to hear presentations from
RMMSC neurologists on the latest
advancements in MS treatment and
care, as well as the work being done by
our own research team at the Rocky

Mountain MS Center at University of
Colorado.

We'd love for you to spend the
morning with us at the Education
Summit, and if you can't make it
in person, you can join us on our
YouTube livestream from your own
computer or mobile device. See page
15 for more information.

MS4MS 2020

Finally, I'd like to remind you about
our 2020 Multiple Summits 4 Multiple
Sclerosis (MS4MS) campaign. All
summer long, we'll have teams of hikers
throughout Colorado and the rest of
the country hiking to raise awareness
and support for the RMMSC. Whether
you hike one of Colorado's 14,000-foot
peaks, or stroll a few laps at your local
park, you can participate!

MS4MS is a fun and challenging way
to get your family and friends involved
in supporting the RMMSC. When you
register on our website, you can set up
your own team, invite people to join you,
and schedule your own hike — all while
raising awareness and funds for programs
and services at the MS Center. MS4MS
registration opens April 1, find out more
on page 14 and keep an eye on our social
media and email alerts for more.

Sincerely,

Gina Hensrud,
Chief Executive Officer

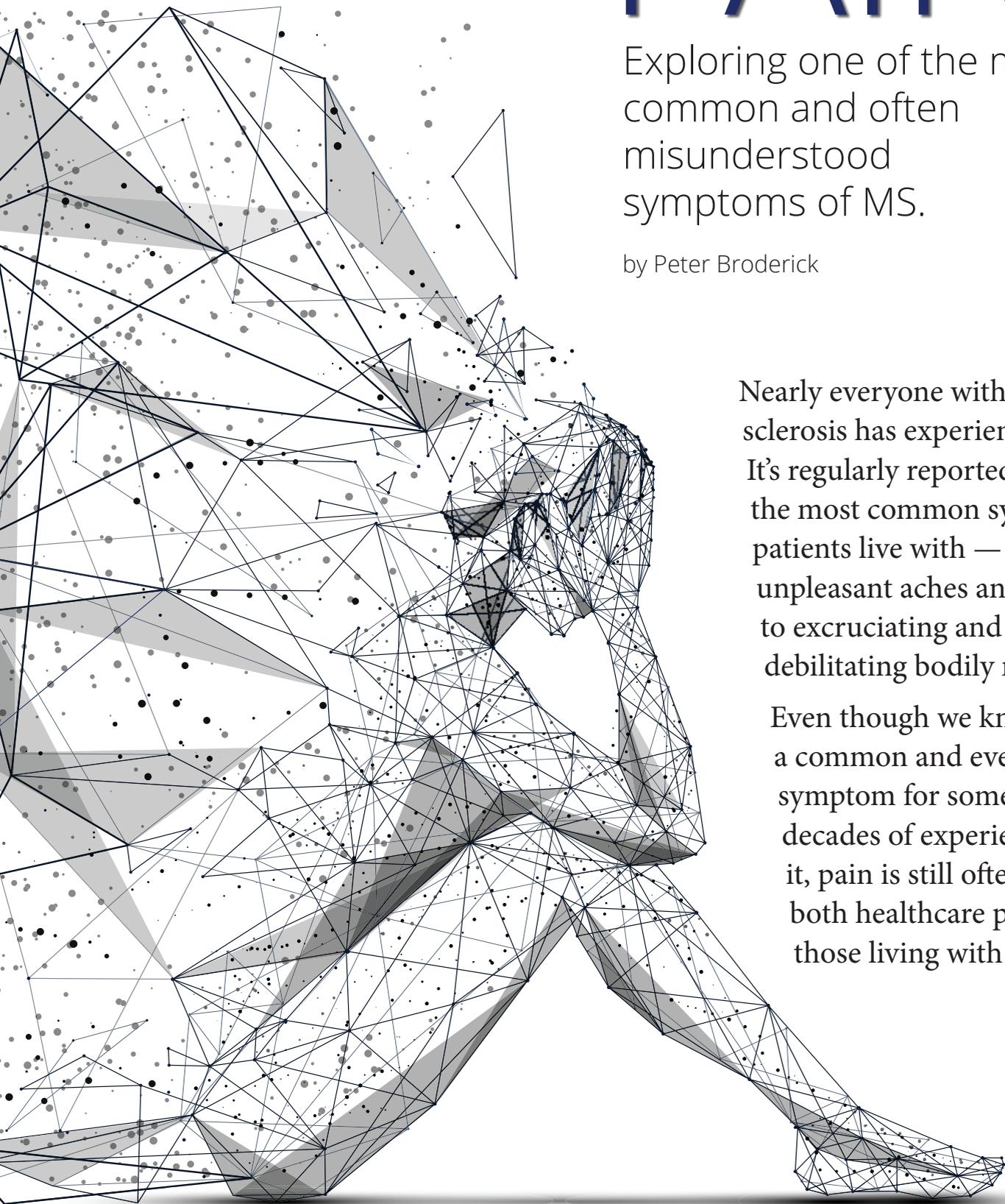
PAIN

Exploring one of the most common and often misunderstood symptoms of MS.

by Peter Broderick

Nearly everyone with multiple sclerosis has experience with pain. It's regularly reported as one of the most common symptoms MS patients live with — ranging from unpleasant aches and sensations, to excruciating and even debilitating bodily misery.

Even though we know pain is a common and even primary symptom for some, and with decades of experience treating it, pain is still often a mystery to both healthcare providers and those living with it every day.



“There’s a lot of misunderstanding about what pain in multiple sclerosis is,” says Anastacia Wall, Physician Assistant with the Rocky Mountain MS Center at University of Colorado.

We expect pain to be a simple cause and effect: you stub your toe on the leg of a chair, and therefore your toe hurts. You strain your back picking up a heavy object, therefore you’ve got back pain. Splash boiling water on yourself while preparing dinner, and the source of that pain is clear and obvious.

Unfortunately, pain that’s a symptom of MS is much more complicated than that.

UNDERSTANDING PAIN IN MS

Most people live in a world where pain is generally easy to explain. And those living with MS are from that world, too. This idea of pain coming from nowhere, or not being the result of something easily understandable and explainable — that’s just as foreign to a newly-diagnosed MS patient as it is to anyone else.

But it’s important to understand that MS pain can come from seemingly nowhere, with no simple explanation as we understand it. Often there’s no underlying injury, accident, muscle strain, or anything else we’d expect to cause pain.

“Sometimes it’s a burning pain, sometimes it’s an electrical pain. I had one patient who complained that his hand was swollen, and he wanted a water pill to bring the swelling down.” said Wall.

But looking at the patient’s hands, everything was normal. “I said, ‘Have you noticed that your wedding ring comes on and off? Don’t you think that’s odd, for a swollen hand?’”

“This was confusing for him — he knew, if his hand was swollen, his wedding ring shouldn’t be able to come on and off. But in his brain, his hand was twice the size it should be,” said Wall.

“That was early in my career, and to me, that was just so illustrative of how the brain can perceive sensation.”

“The most extreme thing that I hear from patients is, ‘Can’t you just cut off my feet?’” said Wall. “As a human being, that’s so jarring... and as a provider, that makes you feel so helpless. But the thing I have to, sadly, say to them, is the pain isn’t in your feet.”

So, without an obvious injury or cause for inflammation, where is this pain coming from? How and why do we feel any of the myriad sensations we call “pain” when there shouldn’t be any pain present?

TWO TYPES OF PAIN

The way the human body perceives pain can be broken down into two main categories, nociceptive pain and neuropathic pain.

Nociceptive pain, or acute pain, is what most of us learned about way back in our most basic biology classes.

Each of our bodies has a vast network of nerves, and those nerves deliver sensations to our brain. Nerve endings in the hand you splashed hot water on send a message to your brain to let you know what hurts, where it hurts, and how bad the pain is.

You can look at it as a sort of an alarm system — pain in your hand alerts us to a problem. First and foremost, get your hand away from that hot water. Next, the severity of the pain lets you know what you need to do. If it’s not so bad, maybe you can just carry on cooking. If it’s moderate, a few minutes of cold water in the sink could suffice. If it’s severe, it might be time to look at first aid or even seek help.

For most people, this is the natural process of feeling and reacting to pain. It’s mostly straightforward, mostly easy to understand, and often fairly easy to treat.

“Most people are living in a world where nociceptive pain is the only pain they experience,” says Wall.

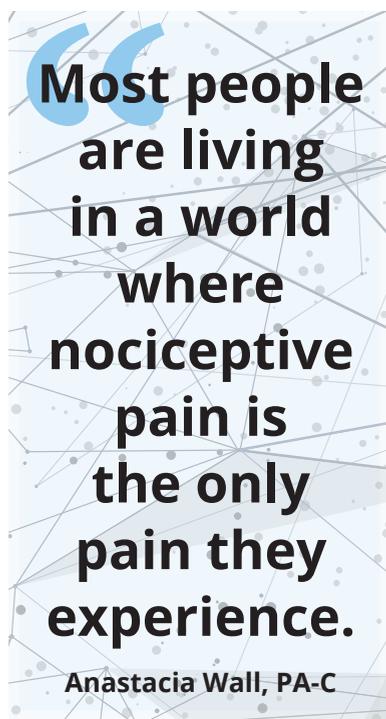
Neuropathic pain, sometimes labeled chronic pain, is what’s often happening with MS patients.

The vast network of nerves responsible for delivering sensations flow from all over our bodies (the peripheral nervous system) into our spinal column and eventually up to our brain (the central nervous system). Neuropathic pain manifests when there’s damage or inflammation along this network.

If acute pain is an alarm system, we can look at this like a malfunction of that alarm. We perceive the pain, and we’re naturally inclined to react — but there’s nothing for us to react to, except the pain itself.

Of course there can be many causes of chronic, neuropathic pain. An injury from long ago may have left you with damaged nerves, or another condition like diabetes may be causing damage somewhere in your peripheral nervous system.

Continued on page 9.



Do you have a parent, sibling or child with MS?



The University of Colorado is conducting a study that will try to improve our understanding of the very earliest signs of Multiple Sclerosis (MS) by looking at individuals at high risk of developing MS, especially young adults with relatives already diagnosed with MS.

You may be eligible to participate if you:

- » Are 18-30 years of age
- » Have a parent, sibling or child with Multiple Sclerosis
- » Have not been diagnosed with MS and have no symptoms concerning for MS

The visit will take place on the University of Colorado Anschutz Medical Campus. Eligible participants will receive a brief brain MRI without contrast.

Want to learn more about this clinical trial?

Please contact:

The RMMSC @ CU Resesarch Team on the University of Colorado Anschutz Medical Campus by calling (303) 724-4644 or e-mailing NeurologyResearchPartners@ucdenver.edu.

ROCKY MOUNTAIN
MS CENTER
— the answers begin here —

University of Colorado Denver
Principal Investigator: John Corboy, MD

Continued from page 7.

But MS, as we know, is an inflammatory disease of the central nervous system. When MS attacks nerves in the brain or spinal cord, neuropathic pain is often the result.

Neuropathic pain can range in severity and sensation. It can be felt as a crawling or burning sensation, pins and needles, and throbbing or stabbing sensations in the arms and legs.

It's responsible for the infamous "MS Hug" — a feeling of tightness around the chest, often experienced by MS patients. It can also manifest as trigeminal neuralgia, a painful sensation of burning or stabbing usually on one side of the face.

Depending on where MS has affected your nerves, neuropathic pain related to MS can vary as widely from person to person as any other common MS symptom.

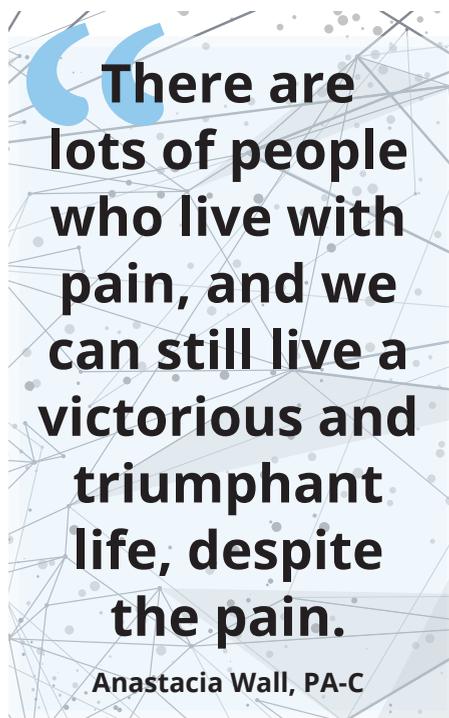
TREATING DIFFERENT TYPES OF PAIN

Why is it so important to understand the differences between the types of pain?

Simply put, it's because how you treat one might have no effect on the other, or even cause additional problems.

"When you have nociceptive pain, you need pain blockers, pain meds, anti-inflammation," says Wall. This can include over the counter medications like ibuprofen and acetaminophen, or or prescription painkillers. Opioids may also be prescribed in some specific cases, but should always be used with great care. Cannabis has shown some anecdotal promise in the treatment of pain, but it still hasn't been studied very thoroughly, leaving its status as a viable pain treatment option murky at best.

The best medication option is different for each individual, and you should discuss specifics with your medical team. But with all pain medications, the aim is to decrease inflammation, which in turn decreases pain.



Generally speaking, these approaches don't work with neuropathic pain.

"When you have neuropathic pain, you can decrease inflammation all you want, it's not going to do it," says Wall. "You can't decrease inflammation in the central nervous system with enough ibuprofen, it's just not going to happen."

Without an underlying cause like an injury that can be directly treated or repaired, treating chronic, neuropathic pain is complicated and difficult. But understanding that this boils down to a malfunction in the nervous system, providers can look elsewhere for treatment — outside the normal regimen of painkillers.

"We have to use seizure medications, or medications that work on neurotransmitters, to try to modify that pain," says Wall. "It's not easy to do, and sometimes we can't. It's a very challenging problem to try to effect."

Seizure medications can interrupt abnormal electrical transmissions and block some electrical impulses that are perceived as pain.

"We also use antidepressants, which people are often surprised by," says Wall. "But the reason is that it's all neurotransmitters, it's all chemistry,

and we can only adjust some things more than others. Sometimes when we increase dopamine or increase serotonin, it can decrease the amount of pain someone will experience."

Treating neuropathic pain isn't without side effects, says Wall, and providers must take care to weigh the benefits of treatments. "Everything we do to try to decrease your pain is going to decrease your cognition."

"Sometimes people say 'I want out of this pain,' but they don't realize there's always a trade-off. If I'm decreasing your electrical impulses in your brain, I can't be specific. We can't just take out your pain receptors, for example, and have no impact on your energy."

The goal, then, is to decrease the perception of neuropathic pain, while limiting the potentially negative side effects on the rest of the nervous system.

"If you're living at an eight (on the pain scale), a four sounds like heaven to you," said Wall. "My goal is always to get patients to a zero, but in some cases that four might be acceptable."

INTERVENTIONS

Medication is only one means of dealing with pain. While it may become necessary, other interventions can play a role in your overall strategy to fight pain.

While any strategy is based on your personal situation and the severity of your conditions, the first of these strategies is simple distraction.

"Most people will say they have a lot of their neuropathic pain in the evening," says Wall. "From my standpoint, the reasons are twofold. One is your brain is developing toxins during the day, which flush out when you sleep. Second, when you're out during the day, running around, doing things, you've got light, you've got sound — you're distracted. When you get home, you're laying in bed, it's basically sensory deprivation, and then all you have is your pain."

Continued on page 10.

The pain scale shown below is a common way of rating or quantifying your pain so you can get on the same page with your provider. On this scale, zero means you're pain-free, while anything above seven is considered severe pain.

0 Pain Free	1 Very Mild	2 Discomforting	3 Tolerable	4 Distressing	5 Very Distressing	6 Intense	7 Very Intense	8 Utterly Horrible	9 Excruciating Unbearable	10 Unimaginable Unspeakable
No Pain	Minor Pain			Moderate Pain			Severe Pain			
Feeling perfectly normal	Nagging, annoying, but doesn't interfere with most daily living activities. Patient able to adapt to pain psychologically and with medication or devices such as cushions.			Interferes significantly with daily living activities. Requires lifestyle changes but patient remains independent. Patient unable to adapt to pain.			Disabling; unable to perform daily living activities. Unable to engage in normal activities. Patient is disabled and unable to function independently.			

Continued from page 9.

“So why not use that to your advantage? If you can distract yourself, or try to use mindfulness strategies to get away from it, I think that’s one of the things that we can do.”

Another important strategy for dealing with pain is simple stretching, exercise and physical activity.

In addition to increasing overall brain health, exercise increases endorphins and serotonin that can dampen some of the effects of neuropathic pain.

“We’re always pushing for overall brain health,” says Wall, and regular physical activity is a core component of that.

GETTING TO THE BOTTOM OF YOUR PAIN

Understanding how different types of pain are treated, it becomes particularly important to properly identify the type of pain you’re in — and that’s not always as easy as it sounds.

It’s also important to remember that not all pain you may experience is related to your MS at all. “Not everything that happens to you is your MS,” says Wall. “Sometimes you still have to go through the things that people without MS go through.”

According to the American Chiropractic Association, up to 80% of the population of the United States will experience back pain at some point in their lives. Pain in your back, then, could just be simple back pain, and

completely unrelated to MS.

Then again, other symptoms of your MS could be exacerbating things and causing unrelated ailments to get worse.

Spasticity, for example, is a tightening or tensing of muscles frequently reported by MS patients. If you experience a severe bout of spasticity, that can easily lead to muscle soreness, joint pain, or other aches and pains that are due to, but not directly related to, your MS.

There are also some simple ways to determine if you’re experiencing acute, nociceptive pain, or chronic neuropathic pain that could indicate it’s a direct symptom of MS.

“If your foot hurts, and you push on it, and it hurts more, it’s not likely to be neuropathic pain,” says Wall. “That tells you that the source of the pain is in your foot, rather than in the central nervous system.”

The process of figuring out your pain can often start with a visit to your primary care physician. Regular exams may show that what you’re dealing with is not directly related to your MS at all.

If that turns out to be the case, there’s likely a treatment available to you that will have a much greater impact on the underlying cause of your pain than resorting to neuropathic treatments.

However, if you and your primary physician have investigated all the possibilities and still haven’t found the

answers you’re looking for, it may be time to take it up with your MS care team.

“I spend a lot of time thinking outside the MS box,” says Wall. “I’m always looking for the thing that’s modifiable.”

“Start with your regular doctor, and if it’s nothing else, if nothing else makes sense, then come to me, then we can see if treating you with neuropathic pain medications is the right way forward.”

HELP YOUR MS TEAM HELP YOU

Pain is notoriously difficult to diagnose, especially when the causes aren’t clear. You can do yourself and your MS care team a great service by trying to help them understand your pain, where it’s coming from, and how it’s affecting you.

“What I want patients to do is to come prepared,” says Wall. “When did it start? What makes it worse? What makes it better? Have you tried over-the-counter pain medications?”

Understanding your personal medical history and the history of the pain you’re currently experiencing will go a long way toward helping your provider find a way forward that best suits your situation. Be prepared with specifics — even keeping notes or a journal of your pain.

“You may live with pain, but that’s not going to end your life,” says Wall. “There are lots of people who live with pain, and we can still live a victorious and triumphant life, despite the pain.” ■



Neuro-Palliative Care

A holistic approach to pain

by Kerri Cechovic

Palliative Care is an approach to treating serious and chronic illnesses through a holistic, team-based approach. Neuro-palliative Care is an extension of this discipline that deals specifically with neurological diseases like multiple sclerosis. We recently sat down with Dr. Christina L. Vaughan, MD, MHS, Chief of Neuro-Palliative Care at CU Hospital.

InforMS: Could you please describe Palliative Care and the Neuro-Palliative Care Clinic?

Dr. Vaughan: Palliative care is an approach to care where we focus on the whole person and all forms of stress and suffering that they are going through. We try to support the patient and their close network – care partners and family members. Neuro-palliative care, in our clinic specifically, is meant to focus on a population of patients with a chronic life-limiting neurologic disease.

Palliative care is a very team-based approach - with a physician, a nurse, an advanced practice provider, a social worker, chaplain, and psychologist. Our role is to try and identify people who could benefit from this team approach, and come alongside the neurologist who is treating their main illness. It might be a consultation and other times we come alongside and stagger visits with the MS team.

Patients with progressive disease are often a good fit for the clinic, since many patients have a high level of needs. We also see patients with very complex symptoms that aren't responding to the first couple rounds of intervention. These are people who have pain, fatigue, depression or other complex symptoms that need attention.

InforMS: Is neuro-palliative care common?

Dr. Vaughan: It is an area that's growing exponentially - there's a lot of interest, and it just makes sense. Neuro-palliative care clinics on the national level are rare, but there are more on the horizon.

Palliative care grew out of the cancer community, which also makes sense but when you expand it to think about neurological diseases, these are really hard illnesses to deal with. There is a lot of complexity for our patients.

InforMS: In your clinic, how do you assess different types of pain that people

are experiencing?

Dr. Vaughan: The palliative care approach really comes into play in the arena of pain. There is a concept called "Total Pain." When people can complain of pain, it is rarely ever just physical pain - it can also be emotional, spiritual, and existential. With a palliative care approach, we are trying to get at all of these different facets of suffering. We bring in our different disciplines - our spiritual care counselor, our social worker, our nurse, and a physician - to help patients address all of the elements.

We want to help embolden the patients to know how to explain their pain to clinicians. And, it is also up to us as clinicians to know how to ask the right questions. There are so many questions you can ask about pain:

What is the character of your pain — is it dull, achy, stabbing, or burning?

Continued on page 13.

Giving Mobility Back To People with Multiple Sclerosis

Your typical standing power chair is an automated device that helps its user move from a seated to standing position and back again. Some standing power chairs also enable users to fully recline.

The Redman Power Chair goes much further. It doesn't just facilitate standing and reclining, it offers a patented body-positioning system that enables a greater range of motion than other chairs.

Stand Up for Your Health

When power chair-using MS patients add standing to their daily routine, better health often follows. They enjoy better circulation, improved bowel and bladder function, higher bone density, greater muscle and joint flexibility, and enhanced morale.

Many say the improved quality of life is the greatest benefit. From their standing chairs, they can look friends and family in the eye and be taken more seriously.

Sports lovers? They aren't avoiding the stadium anymore. When their team scores, they can stand up and cheer like everyone else.

Then there's the man who wasn't satisfied with merely attending his daughter's wedding. Using his power chair, he walked his daughter down the aisle and got the reception off to a rollicking start with the traditional father-daughter dance.

Going Here, There, and Everywhere

Standing power chair users love the fact that they can stand. But they sure aren't standing still. That's because they don't think of power chair life as confinement. Instead, they call it liberation.

And they're taking that mindset out into the world. Standing chair users are enjoying everything from a regular day at the office to participating in conventions.

We've heard from many people who've gone hiking – and some who've enjoyed scuba diving trips.

Since Redman Power Chair users like to get out and about, the Chief 107-ZRx is designed to help them do just that. The seat base height is a standard 18 inches, making it easy to get under restaurant tables and school or office desks.

Redman chairs fit into a much smaller footprint than competing models. The Redman footprint is only 23 inches wide and 39 inches long, so you can easily maneuver those tight squeezes.

Every Redman Power Chair is custom-fitted to you and can be adapted to a wide variety of terrain. So, if your day includes a walk in the woods or work in your garden, Redman can take you there, standing up.

The Original, One-Chair Pioneer

In 1984, Redman revolutionized the power chair industry by introducing the first standing chair. That has been the company's focus ever since. Rather than offering a confusing array of makes and models, Redman builds just one uniquely advanced Standing Power Chair, the Chief 107-ZRx. Our design and functionality improvements have come directly from you – our valued customers – over 35 years.

The Chief 107-ZRx is the only power chair with a patented body positioning system. It's a chair that's designed to move with the user. The chair's versatility extends to operational controls as well. It can be controlled by eye gaze, movements of the tongue or head, by hand, or by foot.

Unlike competitors' chairs, the Redman system mechanically – and automatically – compensates for body position. With a Redman Power Chair, users can enjoy unassisted standing, reclining, tilting, and stretching. And every movement and position offers positive clinical health benefits!

Experience the Redman Difference!

- We build the smallest, lightest power chairs in the industry
- Our chairs move intrinsically to mimic your body
- Each chair is built to fit the individual – no mass production
- The only mid-wheel chair that elevates, tilts, stands & reclines
- Custom-manufactured in the USA by a family-owned company
- Unique positions that no other chair offers
 - Yoga, Stand & Stretch, Tilt-in-Space

Redman Power Chairs are proudly made in Tucson, Arizona, and sold all across the United States. We provide our expertise and services directly to you, with no middleman – including evaluation and fitting, delivery and setup with a complete fit/function guarantee, plus repair and maintenance through a nationwide network of trained staff.

We offer live customer support 24/7/365 and accept all major credit cards and insurance plans. In fact, we're one of just a few power chair companies with an in-house insurance department.




REDMAN[®]
POWER CHAIR

*Schedule a free, no obligation,
in-home demonstration today!*

(800) 727-6684
Info@RedmanPowerChair.com

Continued from page 11.

On a scale of zero to 10 with 10 being the worst pain of your life, where does your pain fall right now? What number would be acceptable to you? What is our target? Obviously zero would be ideal, but outside of zero, what's our goal?

We are very specific and objective about pain with our assessment. But we also ask other eye-opening questions like: What does your pain mean to you? How do you interrupt this pain? How do you make sense of this pain?

Those are the questions we ask that might differ from a typical clinician. It's remarkable the responses you might get.

InforMS: How do patients respond to those questions?

Dr. Vaughan: The answers are wide-ranging. Some people might look at you funny — why are you asking me this and what are you talking about?

Other people might say, "I'm feeling punished by God," and make it something really existential. Or, "this pain means that my disease is getting worse and I don't want to admit to that, so I'm not going to be so forthcoming about this pain."

There are many unexpected ways in which people can interpret their pain, and these conversations often help us identify additional areas of suffering. We are able to bring in our team members, such as our chaplain, social worker, or psychologist to try to help patients with those issues.

With these questions, we are assessing how they interpret their pain, what it means to them, how it's impacting their daily life, how it's affecting people around them, and how it plays out in their life.

Then, we get into the specifics of what number is your pain, what's the character of the pain, what makes it better, what makes it worse, what have you tried, how has that helped?

If we are really going to do a good job in dealing with pain, we are going to spend a lot of time exploring it, which in and of

Asking people to let us in and really understand their pain with them is really helpful in the treatment. Plus it helps them feel heard, and that in and of itself is therapeutic.

itself sounds painful, but it's really not meant to be. You learn so many things when you ask the right questions, and I think palliative care has taught me and continues to teach me how to ask new questions.

In neurology, we walk around with our tuning fork and our hammer, and these are our tools. But in palliative care, to those tools we add questions, those are our tools. Asking people to let us in and really understand their pain with them is really helpful in the treatment. Plus it helps them feel heard, and that in and of itself is therapeutic.

InforMS: Once you've conducted this holistic assessment of the patient's pain, what strategies do you use to help treat or manage their pain?

Dr. Vaughan: The complexity and variation of pain leads to a necessarily multi-faceted and personalized approach for treatment and management.

The character of the pain is different, the cause of the pain is different, and the treatment is different; because there are medications and strategies that are particularly effective for nerve pain or neuropathic pain and not effective for muscular skeletal or nociceptive pain and vice versa.

Meditation and mindfulness techniques can be very helpful for patients. Our

spiritual care counselor discusses these techniques and practices with patients. I also refer many patients to integrative medicine for acupuncture. Massage can also be a very helpful for people. Strategies are very personalized for the individual. We encourage an individualized exercise program for patients since exercise is a helpful strategy.

Depending on the type of pain, we may look at medication options for patients. Medications can range from anti-inflammatory agents to anti-depressants to, as a last resort, opioids. When we evaluate medications, we want to make sure that the benefits outweigh the risks. There is so much fear around opioids because we have a terrible epidemic of opioid use and addiction. At the same time, in my opinion, there is an emerging epidemic of under-treatment of pain. Again, I want to emphasize that medications certainly are not the only solution to pain management and there are various other modalities. But when you're talking about medications, there is a staircase approach — starting with things like Tylenol or Ibuprofen and then careful consideration and evaluation on escalating up.

We also look at practical daily strategies for navigating life while managing pain. With unpredictable pain, you never know when it's going to flare up, and we know that that pain may cause people to be isolated and stay at home and not want to go out. This isolation can contribute to increased fatigue and depression. Our treatment approach includes working with them to develop practical solutions, such as developing a contingency plan for if their pain flares when they are outside of their home. ■

For more information on the Neuro-Palliative Care Clinic at UCHHealth, please ask your provider or call Alan Hall at 720-848-8761 to schedule an appointment, or visit www.neuropalliative.org.

MULTIPLE SUMMITS 4MS

Registration opens April 1st
www.mscenter.org/summits



Team Medtronic atop Quandary Peak in 2017.

Hit the trails with us this summer and hike for a cause!

MS4MS is a do-it-your-way approach to raising awareness and support for the Rocky Mountain MS Center. Teams and individuals are setting their sights on trails across Colorado and beyond!

Sign up for yourself, then create a team, join an existing group of hikers, or head to a trail on your own. Friends and family can support your efforts right on your personal fundraising page.

CONQUER YOUR SUMMIT CONQUER MS



The MS Young Professionals Network hike in 2017.

Hike a 14er

Take your MS4MS team to new heights, hiking one of Colorado's "14ers." If you're not in Colorado, no problem! Find a hike near you, and see how close to 14,000 you can get. Or you can go for the MS4MS record: 19,341 feet atop Mount Kilimanjaro in 2016!

Hike a Flat 14er

If altitude's not your thing, you can still join us! Map a route on flat ground — 14,000 feet is just a little under three miles. Clients at the RMMSC's King Adult Day Enrichment Program (KADEP) hike a Flat 14er every year. Join us on a trail near you!



All MS4MS participants get a personal fundraising page, MS4MS t-shirt, and MS4MS bumper sticker (pictured).



Form a team, invite your friends
and get started hiking for a cause at
MSCenter.org/summits

Alleviating Pain through Hydrotherapy: Jane's Story

Jane was diagnosed with multiple sclerosis twelve years ago at the age of 64.

"First I experienced numbness in my feet and then it progressed to my leg. After seeing a podiatrist at first, he recommended that I see a neurologist," says Jane.

"My right leg is my weak leg and that's where I experience the pain which is intense cramping," explains Jane. "I take baclofen, but I've found that I can eliminate most of the pain if I do my stretching exercises for my hip flexors."

Jane has been attending RMMSC's Hydrotherapy Program with physical therapist, Michele Harrison, for about two years. "The aquatic exercise really helps to lessen my pain considerably. When I don't go to class, for a week or two, I notice it a lot."

"I'm able to do certain motions in the water that I can't do on land." For

example, Jane uses a special resistance device on her feet and moves like she is cross country skiing in the water. "This exercise strengthens my leg and forces me to work through some of that pain."

"I used to be a runner and I'm not able to do that anymore. I've found that hydrotherapy is a great alternative. The water is buoyant so I can get an aerobic workout in water that I can't get on land. And I've been able to strengthen my right leg by doing exercises in the water."

Hydrotherapy offers a whole range of exercises that people can do – band work to strengthen arms and legs, aerobic exercises such as walking and powerwalking in the water, and the wonderful stretches that we do. Everyone has different focus areas that they are working on, so there are many different pieces of equipment to meet individuals' abilities and needs.

"Hydrotherapy has been very beneficial



for me. The bottom line is that if I don't go, I have more pain. The motivation for me is that I just feel so much better." ■

For more information about the RMMSC's Hydrotherapy program, visit our website at MSCenter.org/hydro. Volunteers are needed to assist with Hydrotherapy in the Denver area! If you're interested in helping, please contact Michele Harrison at (720) 273-7461.

MS EDUCATION SUMMIT

Join us for a series of presentations and discussions with leading minds in the care and treatment of multiple sclerosis at the Rocky Mountain MS Center Spring Education Summit.

Saturday, April 18
9 a.m. to 12:15 p.m.

Join us at the Krugman Conference Hall at University of Colorado Anschutz Medical Campus.
Research 2 Building, Second Floor
12700 E 19th Ave, Aurora, CO 80045

REGISTER TODAY for this FREE EVENT!

Choose one of these convenient ways to register:

1. Register Online at our website: www.mscenter.org/edsummit
2. Send an Email with your attendance option (in-person or streaming), name, address, phone number and the number of people attending to register@mscenter.org
3. Call us at 303-788-4030 ext, 120



Can't join us in person? Watch the Education Summit on YouTube Live! Choose the Livestream option when you register at www.mscenter.org/edsummit

FEATURED PRESENTATIONS:

- **Maximizing Lifelong Brain Health**
with Dr. Timothy Vollmer
- **Symptom Management, Mental Health & Cognition**
with Dr. Enrique Alvarez
- **DMT Discussion**
with Dr. John Corboy
- **Exercising and Fatigue**
with Dr. Jeff Hebert
- **Biology of MS and Related Diseases**
with Dr. Amanda Piquet

The Education Summit is made possible in part by grants from:

 **Biogen**
Celgene
EMD Serono
Genentech



Slowing down active SPMS

For adults.
Not an actual patient.

What is MAYZENT® (siponimod) tablets?

MAYZENT is a prescription medicine that is used to treat relapsing forms of multiple sclerosis, to include clinically isolated syndrome, relapsing-remitting disease, and active secondary progressive disease, in adults. It is not known if MAYZENT is safe and effective in children.

IMPORTANT SAFETY INFORMATION

Do not take MAYZENT if you:

- have a CYP2C9*3/*3 genotype. Before starting treatment with MAYZENT, your CYP2C9 genotype should be determined by your health care provider. Ask your health care provider if you are not sure.
- have had a heart attack, chest pain called unstable angina, stroke or mini-stroke (transient ischemic attack or TIA), or certain types of heart failure in the last 6 months
- have certain types of heart block or irregular or abnormal heartbeat (arrhythmia), unless you have a pacemaker

MAYZENT may cause serious side effects, including:

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

During the initial up dosing period (4 days for the 1-mg daily dose or 5 days for the 2-mg daily dose), if you miss 1 or more doses of MAYZENT, you need to restart the up dosing. Call your health care provider if you miss a dose of MAYZENT.

2. Infections. MAYZENT can increase your risk of serious infections that can be life-threatening and cause death. MAYZENT lowers the number of white blood cells (lymphocytes) in your blood. This will usually go back to normal within 3 to 4 weeks of stopping treatment. Your health care provider should review a recent blood test of your white blood cells before you start taking MAYZENT.

Call your health care provider right away if you have any of these

symptoms of an infection during treatment with MAYZENT and for 3 to 4 weeks after your last dose of MAYZENT:

- fever
- tiredness
- body aches
- chills
- nausea
- vomiting
- headache with fever, neck stiffness, sensitivity to light, nausea, confusion (these may be symptoms of meningitis, an infection of the lining around your brain and spine)

3. A problem with your vision called macular edema. Macular edema can cause some of the same vision symptoms as a multiple sclerosis (MS) attack (optic neuritis). You may not notice any symptoms with macular edema. If macular edema happens, it usually starts in the first 1 to 4 months after you start taking MAYZENT. Your health care provider should test your vision before you start taking MAYZENT and any time you notice vision changes during treatment with MAYZENT. Your risk of macular edema is higher if you have diabetes or have had an inflammation of your eye called uveitis.

Call your health care provider 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, or unusually colored (tinted) vision.

Before taking MAYZENT, tell your health care provider about all of your medical conditions, including if you:

- have an irregular or abnormal heartbeat
- have a history of stroke or other diseases related to blood vessels in the brain
- have breathing problems, including during your sleep
- have a fever or infection, or you are unable to fight infections due to a disease or are taking medicines that lower your immune system. Tell your health care provider if you have had chickenpox or have received the vaccine for chickenpox. Your health care provider may do a blood test for chickenpox virus. You may need to get the full course of vaccine for chickenpox and then wait 1 month before you start taking MAYZENT.
- have slow heart rate
- have liver problems



means
holding on to
more moments
like this



The first and only pill studied and proven in active SPMS

In the overall study, nearly **3 out of 4 people taking MAYZENT®** showed no 3-month confirmed disability progression.*

Talk to your doctor about holding on to more moments with MAYZENT. Visit mayzent.com to learn more.

 **MAYZENT®**
(siponimod) tablets
0.25 mg • 2 mg

*74% of people taking MAYZENT, compared to 68% of people taking placebo. SPMS=secondary progressive multiple sclerosis.

The effect of MAYZENT was significant in patients with active SPMS and not considered significant in patients with nonactive SPMS.

- have diabetes
- have eye problems, especially an inflammation of the eye called uveitis
- have high blood pressure
- are pregnant or plan to become pregnant. MAYZENT may harm your unborn baby. Talk to your health care provider right away if you become pregnant while taking MAYZENT or if you become pregnant within 10 days after you stop taking MAYZENT.
 - o If you are a woman who can become pregnant, you should use effective birth control during your treatment with MAYZENT and for at least 10 days after you stop taking MAYZENT.
- are breastfeeding or plan to breastfeed. It is not known if MAYZENT passes into your breast milk. Talk to your health care provider about the best way to feed your baby if you take MAYZENT.

Tell your health care provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, and herbal supplements. Especially tell your health care provider if you take medicines to control your heart rhythm (anti-arrhythmics), or blood pressure (antihypertensives), or heart beat (such as calcium channel blockers or beta-blockers); take medicines that affect your immune system, such as beta-interferon or glatiramer acetate, or any of these medicines that you took in the past.

Tell your health care provider if you have recently received a live vaccine. You should avoid receiving **live** vaccines during treatment with MAYZENT. MAYZENT should be stopped 1 week before and for 4 weeks after receiving a live vaccine. If you receive a live vaccine, you may get the infection the vaccine was meant to prevent. Vaccines may not work as well when given during treatment with MAYZENT.

MAYZENT may cause possible side effects, including:

- **increased blood pressure.** Your health care provider should check your blood pressure during treatment with MAYZENT.
- **liver problems.** MAYZENT may cause liver problems. Your health care

provider should do blood tests to check your liver before you start taking MAYZENT. Call your health care provider right away if you have any of the following symptoms of liver problems:

- o nausea
- o vomiting
- o stomach pain
- o tiredness
- o loss of appetite
- o your skin or the whites of your eyes turn yellow
- o dark urine

- **breathing problems.** Some people who take MAYZENT have shortness of breath. Call your health care provider right away if you have new or worsening breathing problems.
- **swelling and narrowing of the blood vessels in your brain.** A condition called PRES (Posterior Reversible Encephalopathy Syndrome) has happened with drugs in the same class. Symptoms of PRES usually get better when you stop taking MAYZENT. However, if left untreated, it may lead to a stroke. Call your health care provider right away if you have any of the following symptoms: sudden severe headache, sudden confusion, sudden loss of vision or other changes in vision, or seizure.
- **severe worsening of multiple sclerosis after stopping MAYZENT.** When MAYZENT is stopped, symptoms of MS may return and become worse compared to before or during treatment. Always talk to your doctor before you stop taking MAYZENT for any reason. Tell your health care provider if you have worsening symptoms of MS after stopping MAYZENT.

The most common side effects of MAYZENT include: headache, high blood pressure (hypertension), and abnormal liver tests.

These are not all of the possible side effects of MAYZENT. Call your doctor for medical advice about side effects.

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 Consumer Brief Summary on following pages.

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CONSUMER BRIEF SUMMARY

The risk information provided here is not comprehensive. This information does not take the place of talking with your doctor about your medical condition or treatment.

To learn more about MAYZENT® (siponimod) tablets, talk to your doctor or pharmacist. For more information and to obtain the FDA-approved product labeling, call 1-888-669-6682 or visit www.mayzent.com.

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

1. MAYZENT may cause serious side effects, including: Slow heart rate (bradycardia or bradyarrhythmia) when you start taking MAYZENT.

MAYZENT can cause your heart rate to slow down, especially after you take your first dose. You should have a test to check the electrical activity of your heart called an electrocardiogram (ECG) before you take your first dose of MAYZENT.

During the initial updosing period (4 days for the 1 mg daily dose or 5 days for the 2 mg daily dose), if you miss 1 or more doses of MAYZENT, you need to restart the updosing. Call your healthcare provider if you miss a dose of MAYZENT. See **“How should I take MAYZENT?”**

2. Infections. MAYZENT can increase your risk of serious infections that can be life-threatening and cause death. MAYZENT lowers the number of white blood cells (lymphocytes) in your blood. This will usually go back to normal within 3 to 4 weeks of stopping treatment. Your healthcare provider should review a recent blood test of your white blood cells before you start taking MAYZENT.

Call your healthcare provider right away if you have any of these symptoms of an infection during treatment with MAYZENT and for 3 to 4 weeks after your last dose of MAYZENT:

- fever
- vomiting
- tiredness
- headache with fever, neck stiffness, sensitivity to light, nausea, confusion (these may be symptoms of meningitis, an infection of the lining around your brain and spine)
- body aches
- chills
- nausea

3. A problem with your vision called macular edema. Macular edema can cause some of the same vision symptoms as a multiple sclerosis (MS) attack (optic neuritis). You may not notice any symptoms with macular edema. If macular edema happens, it usually starts in the first 1 to 4 months after you start taking MAYZENT. Your healthcare provider should test your vision before you start taking MAYZENT and any time you notice vision changes during treatment with MAYZENT. Your risk of macular edema is higher if you have diabetes or have had an inflammation of your eye called uveitis.

Call your healthcare provider 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

See **“What are possible side effects of MAYZENT?”** for more information about side effects.

What is MAYZENT?

MAYZENT is a prescription medicine that is used to treat relapsing forms of multiple sclerosis, to include clinically isolated syndrome, relapsing-remitting disease, and active secondary progressive disease, in adults.

It is not known if MAYZENT is safe and effective in children.

Who should not take MAYZENT?

Do not take MAYZENT if you:

- have a CYP2C9*3/*3 genotype. Before starting treatment with MAYZENT, your CYP2C9 genotype should be determined by your healthcare provider. Ask your healthcare provider if you are not sure.
- have had a heart attack, chest pain called unstable angina, stroke or mini-stroke (transient ischemic attack or TIA), or certain types of heart failure in the last 6 months
- have certain types of heart block or irregular or abnormal heartbeat (arrhythmia), unless you have a pacemaker

What should I tell my healthcare provider before taking MAYZENT?

Before taking MAYZENT, tell your healthcare provider about all of your medical conditions, including if you:

- have an irregular or abnormal heartbeat
- a history of stroke or other diseases related to blood vessels in the brain
- breathing problems, including during your sleep
- 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 healthcare provider if you have had chicken pox or have received the vaccine for chicken pox. Your healthcare provider may do a blood test for chicken pox virus. You may need to get the full course of vaccine for chicken pox and then wait 1 month before you start taking MAYZENT.
- have slow heart rate
- have liver problems
- have diabetes
- have eye problems, especially an inflammation of the eye called uveitis
- have high blood pressure
- are pregnant or plan to become pregnant. MAYZENT may harm your unborn baby. Talk to your healthcare provider right away if you become pregnant while taking MAYZENT or if you become pregnant within 10 days after you stop taking MAYZENT.
 - If you are a woman who can become pregnant, you should use effective birth control during your treatment with MAYZENT and for at least 10 days after you stop taking MAYZENT.
- are breastfeeding or plan to breastfeed. It is not known if MAYZENT passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby if you take MAYZENT.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, and herbal supplements. Especially tell your healthcare provider if you:

- take medicines to control your heart rhythm (antiarrhythmics), or blood pressure (antihypertensives), or heart beat (such as calcium channel blockers or beta-blockers)
- take medicines that affect your immune system, such as beta-interferon or glatiramer acetate, or any of these medicines that you took in the past
- have recently received a live vaccine. You should avoid receiving live vaccines during treatment with MAYZENT. MAYZENT should be stopped 1 week before and for 4 weeks after receiving a live vaccine. If you receive a live vaccine, you may get the infection the vaccine was meant to prevent. Vaccines may not work as well when given during treatment with MAYZENT.

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

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

How should I take MAYZENT® (siponimod) tablets?

The daily maintenance dose of MAYZENT is either 1 mg or 2 mg, depending on your CYP2C9 genotype. Ask your healthcare provider if you are not sure about your daily maintenance dose.

Start your treatment with MAYZENT using the following titration schedule:

For the 1 mg daily maintenance dose:	Tablets a day
Day 1	1 x 0.25 mg tablet
Day 2	1 x 0.25 mg tablet
Day 3	2 x 0.25 mg tablet
Day 4	3 x 0.25 mg tablet
Day 5 and every day after	4 x 0.25 mg tablet

For the 2 mg daily maintenance dose, use the starter pack:	Tablets a day
Day 1	1 x 0.25 mg tablet
Day 2	1 x 0.25 mg tablet
Day 3	2 x 0.25 mg tablet
Day 4	3 x 0.25 mg tablet
Day 5	5 x 0.25 mg tablet
Day 6 and every day after	1 x 2 mg tablet

- Take MAYZENT exactly as your healthcare provider tells you. Do not change your dose or stop taking MAYZENT unless your healthcare provider tells you to.
- Take MAYZENT 1 time each day.
- Take MAYZENT with or without food.
- If you miss 1 or more doses of MAYZENT **during** the initial dose titration, you need to restart the medication.
- If you miss a dose of MAYZENT **after** the initial dose-titration, take it as soon as you remember.
- If MAYZENT treatment is stopped for 4 days in a row, treatment has to be restarted with the titration.
- **Do not stop taking MAYZENT without talking with your healthcare provider first.**

What are the possible side effects of MAYZENT?

MAYZENT may cause serious side effects, including:

- **See “What is the most important information I should know about MAYZENT?”**
- **increased blood pressure.** Your healthcare provider should check your blood pressure during treatment with MAYZENT.
- **liver problems.** MAYZENT may cause liver problems. Your healthcare provider should do blood tests to check your liver before you start taking MAYZENT. Call your healthcare provider right away if you have any of the following symptoms of liver problems:
 - nausea
 - vomiting
 - stomach pain
 - tiredness
 - loss of appetite
 - your skin or the whites of your eyes turn yellow
 - dark urine
- **breathing problems.** Some people who take MAYZENT have shortness of breath. Call your healthcare provider right away if you have new or worsening breathing problems.
- **swelling and narrowing of the blood vessels in your brain.** A condition called PRES (Posterior Reversible Encephalopathy Syndrome) has happened with drugs in the same class. Symptoms of PRES usually get better when you stop taking MAYZENT. However, if left untreated, it may lead to a stroke. Call your healthcare provider right away if you have any of the following symptoms:

- sudden severe headache
- sudden loss of vision or other changes in your vision
- sudden confusion
- seizure

- **severe worsening of multiple sclerosis after stopping MAYZENT.** When MAYZENT is stopped, symptoms of MS may return and become worse compared to before or during treatment. Always talk to your doctor before you stop taking MAYZENT for any reason. Tell your healthcare provider if you have worsening symptoms of MS after stopping MAYZENT.

The most common side effects of MAYZENT include:

- headache
- high blood pressure (hypertension)
- abnormal liver tests

Tell your healthcare provider if you have any side effects that bother you or that do not go away.

These are not all of the possible side effects of MAYZENT. For more information, ask your healthcare provider 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 MAYZENT?

Before opening:

- MAYZENT 0.25 mg and 2 mg tablets should be stored in a refrigerator between 36°F to 46°F (2°C to 8°C).

After opening:

- MAYZENT 0.25 mg tablets **in the Starter Pack** may be stored at room temperature, 68°F to 77°F (20°C to 25°C), for up to 1 week after opening.
- MAYZENT 0.25 mg and 2 mg tablets **in bottles** may be stored at room temperature, 68°F to 77°F (20°C to 25°C), for up to 1 month after opening.

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

General information about the safe and effective use of MAYZENT

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use MAYZENT for a condition for which it was not prescribed. Do not give MAYZENT to other people, even if they have the same symptoms you have. It may harm them. You can ask your pharmacist or healthcare provider for more information about MAYZENT that is written for health professionals.

What are the ingredients in MAYZENT?

Active ingredient: siponimod

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Answering MS Questions

MS Awareness Month is a chance to bring multiple sclerosis to the forefront, to help advocate for people and families living with MS every day, and to educate the public. This March, we've devoted the month to helping foster greater understanding of MS in our community.

MS is often an “invisible” disease. So many common symptoms can be truly life-altering to those living with them, but not always apparent to the outside world. We've created this page of basic MS information for patients and families living with MS, to help them share the facts about MS with loved ones, friends, co-workers, neighbors, and anyone else who may not have a great understanding of what it means to live with MS.

This MS Awareness Month, we invite you to not only read the information included here, but also to share it with others, especially on social media using the hashtag #MSAwareness. By answering some common questions, together we can build understanding of MS and how it affects those living with it.

MS: THE BASICS

MS is a disease of the central nervous system that disrupts communication between the brain and other parts of the body. The severity of the disease and its symptoms vary from person to person. The cause of MS is unknown and although there are treatments that can slow disease progression, at this time there is no known cure.

WHAT IS MS?

MS is a chronic disease of the brain, spinal cord and optic nerves. Three factors appear to have an influence on developing MS: genetic predisposition, environmental factors such as geographical location, and a trigger, such as a virus.

HOW DOES MS MANIFEST?

The nerve fibers in the central nervous system are protected and made more effective by a fatty substance, myelin, which helps the nerve fibers conduct electrical impulses to and from the brain. MS produces injury in the central nervous system when the immune system mistakenly attacks myelin. Areas of myelin damage are known as plaques, or lesions, and these eventually fill in with scar tissue. The name multiple sclerosis means “many scars.” MS can also cause destruction of the entire nerve. The damage from lesions disrupts the transmission of nerve impulses from the central nervous system to the rest of the body causing a variety of symptoms.

Common MS symptoms often include (among many others):

- visual changes
- heat sensitivity
- muscle weakness
- problems with balance
- fatigue
- muscle spasms
- numbness
- emotional and cognitive changes
- anxiety
- depression

Many MS patients experience “quiet” periods when the disease is relatively dormant, but they may still be coping with one or a number of symptoms that aren't apparent to the outside world. These patients can also have periods where the disease is quite active, known as exacerbations. During exacerbations, symptoms can be more pronounced, but usually subside and sometimes go away entirely soon after an exacerbation. Other patients may not experience dormant periods, and instead live with constant symptoms or a progressive worsening of the disease. MS can sometimes lead to disability, depending on a multitude of factors.

Every case of MS is different and every patient's experience is unique. No person

experiences the same symptoms in the same way, making MS a particularly difficult experience to explain or relate to others. At the Rocky Mountain MS Center, our focus is on treating the disease early and effectively with the aim of halting disease progression and maximizing the lifelong brain health of MS patients.

WHO GETS IT?

MS is most commonly diagnosed in young adults. Eighty percent of MS patients develop MS between the ages of 16 and 45. Women are more frequently diagnosed with MS by at least 2 to 1. MS is the leading cause of disability in young women and the second leading cause of disability in young men.

The worldwide prevalence is around 2.7 million, and nearly a million Americans have been diagnosed with the disease. In Colorado, we estimate that one in about 550 people have MS.

HOW IS MS TREATED?

It's only been since 1993 that medications have been available to treat MS. Today there are more than 15 agents approved by the FDA for the treatment of MS, but these drugs are only partially effective. Research efforts to improve MS treatment are ongoing, and much of that research is being done by the RMMSC right here in Colorado. An encouraging new frontier is exploring potential strategies for neuroprotection and neurorepair.

LEARNING MORE

Visit us at MSCenter.org/msmonth for more detailed information about MS, including links to our education portal, videos, webinars and more. Connect with us on Facebook, Twitter and LinkedIn by searching for “Rocky Mountain MS Center.” Once we're connected, help us spread the word by using the #MSAwareness hashtag. ■

Paying it Forward: Support the MS Center During Awareness Month

MS Awareness provides an opportunity to bring multiple sclerosis to the forefront and offers a time of reflection about your and your family's journey with MS. As you reflect on the incredible advancements in therapies and treatments, it becomes a perfect time to pay it forward and help sustain our ability to provide care, support, education, and research to the MS community for the people who depend on us.

Because of the Rocky Mountain MS Center, the MS Community has a

network of support, access to expert physicians, clinicians and ground-breaking research. They are empowered through our education programs, and they feel connected because of programs like our MS Young Professionals Network (MSYPN). In fact, one of our MSYPN members shared with us why her involvement is so important, "It's been good to talk things through with people. We laugh and cry, and I also value hearing from people who have family members with MS."

Together we can change the landscape

for people living with MS and other neurological disorders. Here are ways you can Pay it Forward.

Donate on our website [MSCenter.org/donate](https://mscenter.org/donate). You can make a gift in honor of your health care provider or a loved one.

The Rocky Mountain MS Center can also accept donations from stocks or retirement funds.

Contact RMMSC Development Director Sarah Heil at 303-788-4030 x 145 or sheil@mscenter.org. ■

ReFUND CO: Use Your Colorado State Tax Refund to Support RMMSC

In 2019, Colorado returned more than \$1 billion in refunds to 1.9 million state taxpayers.

In 2020, Coloradans who receive a state income tax refund will have a chance to donate all or some of it to a local nonprofit they trust like the Rocky Mountain MS Center.



Imagine if state taxpayers chose to donate just a portion of their refunds; this outpouring of support would re-energize local community causes across Colorado and make a massive positive impact on our state.

If you get a state income tax refund, this new program puts you in control of deciding to donate some or all of it and choosing exactly which Colorado-registered charity will directly benefit.

It's as simple as 1,2,3:

1. Decide how much of your refund to donate.
2. Enter "Rocky Mountain Multiple Sclerosis Center" and our registration number — **20033001255** — in the Donate to a Colorado Nonprofit Fund line on your state income tax return or tax software – or just give this info to your tax preparer when you share your tax documents.
3. Smile knowing you've helped a cause that matters to you

For the MS Center, this provides a new way to fund our ongoing work in the community. Whether you do your taxes yourself or use a tax preparer, RefundWhatMatters.org provides simple instructions for how to make sure your refund donation goes to your chosen nonprofit. ■

Friends of the MS Center: Sign Up as a Monthly Donor!



Show your support and commitment to those impacted by MS by becoming a Friend of the Rocky Mountain MS Center! Your monthly donation will automatically be deducted from your checking account or credit card. By becoming a Friend of the MS Center, you are not only taking advantage of a convenient and environmentally-friendly method of giving but it also helps sustain the year-long program, services, education, and research that support our patients, and families.

Why become a Friend of the MS Center?

- It's convenient. Your monthly donation will process automatically, with no calls to make or envelopes to mail.
- It's easier on your budget. Spreading your support over the year monthly makes it easy to give generously.

Benefits of being a Friend of the MS Center

- Early notification of ticket sales to our Annual Gala
- Happy Hour social and networking opportunities with other Friends
- Exclusive Friends of the MS Center email newsletter
- Special gifts to thank you for your dedication and generosity

Joining is easy and safe: your personal information is processed with the highest level of security, **go to mscenter.org/friends** to get started. Please contact Development Director Sarah Heil at sheil@mscenter.org or 303-788-4030 ext. 145 if you have any questions. ■



Disclosing Multiple Sclerosis

Whether and When to Tell Your Employer You Have MS

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

There is no one-size-fits all answer here. In part, this is because emotional factors play a role in the decision. Explaining the origins of a gait abnormality, may serve to end speculation and make working life more comfortable. For example, one client, a dental hygienist with MS, became unable to work with patients because of a tremor. Accordingly, she changed her job and became a teacher instead, without any clinical responsibilities. She told me that on the first day of every class, she explained to her students, “Let me get this out of the way: I am not drunk; I have MS.” She believed that this helped build a trusting rapport with students

and avoided distracting speculation as to why she was clearly unsteady, and increased her own comfort level. This strategy worked in her case.

In many other cases, however, such a disclosure might be ill-advised. Most people know very little about MS. Employers and co-workers may even think that it is a terminal condition. Many don't know that with good treatment, functional loss over time may be minimal or even zero. Uninformed people in your work environment, due to prejudice, may begin to view you as less competent. You may even miss promotions--or

worse--based on this prejudice. Though this may be illegal, you may find it hard to prove. In any case, what you want are strong, supportive relationships with co-workers and supervisors, not a potential legal claim.

Therefore, in my opinion, the better course is not to disclose that you have multiple sclerosis to your employer or co-workers (except, perhaps, to trusted friends who will not disclose to others, especially leadership).

Similarly, for the reasons described above, e.g., prejudice, I do not think it is a good idea to disclose that you have MS at a job interview.

When Disclosure *IS* a Good Idea

On the other hand, there are times when disclosure is a good idea, even necessary, to continue employment. Usually, such a disclosure becomes critical when MS related symptoms and limitations begin to interfere with your ability to do your work, whether your employer has noticed or not. But it is especially critical after a bad review at work. Such a disclosure at this point may afford important legal protections that may significantly extend your ability to continue in the workplace.

For example, fatigue may become so severe as to begin to interfere with job demands. There are multiple possible ways to handle this problem by seeking reasonable accommodations and the Americans with Disabilities Act (ADA), a federal law for larger employers (generally greater than 15 employees) or, for smaller employers under state laws, which, in most states will provide protection for workers who work for smaller employers.

If you notify your employer about the fact that you have MS, you should do so in writing and request a discussion about whether accommodations may be available that might help you stay in your job. Your employer must begin a conversation with you, technically they must “begin an iterative process” with you to identify reasonable accommodations that may help you keep your job. Examples of possible accommodations that might help might include:

- a more flexible work schedule,
- working from home one day per week,
- job restructuring, or
- the use of a wheelchair.

You are entitled to a reasonable accommodation unless it places an undue burden on your employer. Whether these potential accommodations create an undue hardship will be determined on a case by case basis. But the conversation

may identify some solutions that both the employer and the employee consider to be reasonable.

Occasional time off may become a critical strategy for staying in the workforce. For larger employers (those with 50 or more employees) then the protections of the Family Medical Leave Act (FMLA) are critical. This will provide up to twelve weeks unpaid leave over the course of a twelve-month period. Without the FMLA, most employers won't tolerate even once absence per month before firing someone. (*Note that there are also state analogs to the FMLA, which may protect employees at smaller firms.*)

To receive the protections of the ADA or the FMLA, notifying your employer about having MS is required. Generally, at least in my opinion, it is when seeking these protections that you should disclose your MS to your employer, but not before.

It will be important to work with your clinical team as you go seek the protections of either the FMLA or the ADA. Ultimately, they will need to substantiate your diagnosis and the need for accommodations. Ideally, you should discuss this with your clinical team prior to notifying your employer to ensure that your clinicians will support what you are seeking to accomplish. ■

Thomas Stewart directs the RMMSC's Disability Law Program. For a free consultation, please contact RMMSC's Disability Law Clinic at (720) 301-9708.

References and Additional Reading:

<https://www.mscenter.org/images/stories/PDF/InforMSSummer2016.pdf>

<https://www.nationalmssociety.org/Living-Well-With-MS/Work-and-Home/Employment/Disclosure-Decisions/Should-I-tell>



MS CENTER CALENDAR

MS 101 (Three sessions monthly)

Empowerment through Education for the Newly Diagnosed. Join the Rocky Mountain MS Center for an informal discussion of issues important to people newly diagnosed with MS. The small group format of MS 101 allows each class to be tailored to the needs of attendees. There is no charge, but registration is required and class size is limited. Call 303-788-4030 x 120 to learn more. *Aurora, Denver & Online*

Conversations on MS (Monthly)

Do you have questions about the latest in MS research, symptom management, clinical care options and more? Throughout the year we travel the region bringing the Conversations on MS program to communities around the Rocky Mountain region. Visit www.mscenter.org/events/calendar for dates. *Locations around the region*
Next Session: COLORADO SPRINGS, Thursday, May 14, at the Penrose Library, 20 N. Cascade Ave., 6 to 7:30 p.m.

MS Education Summit (Saturday, April 18) Join leading minds in the care and treatment of MS for a morning of presentations and discussions. Join us in person on the Anschutz Medical Campus in Aurora, or watch from home on our YouTube Live livestream. Register today at mscenter.org/edsummit. *Aurora & Online*

RMMSC Webinars (Monthly and Archived Online)

The Rocky Mountain MS Center webinar series is a convenient way to hear directly from some of the top minds in the MS world, on topics that are relevant to you. Join us online at mscenter.org/webinars, where you'll find RMMSC's archived Webinars as well as the latest schedule of upcoming events. *Online*

Register for these events and see our complete calendar at mscenter.org/calendar.

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*March is MS Awareness Month!
See page 20 for information on spreading the word and supporting the MS Center.*

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PAIN

Exploring one of the most
common and often
misunderstood
symptoms of MS.

