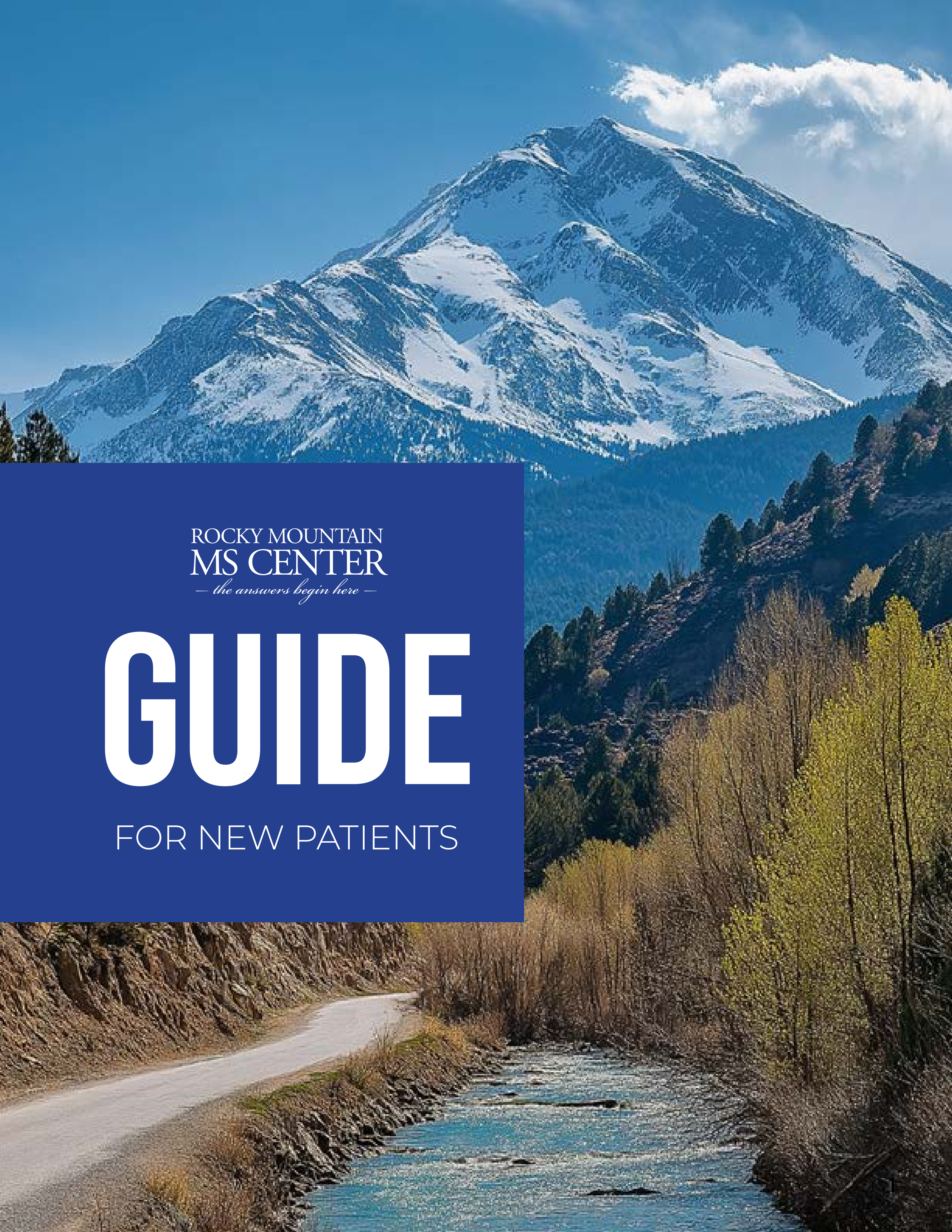

ROCKY MOUNTAIN
MS CENTER
— *the answers begin here* —

GUIDE

FOR NEW PATIENTS

PROGRAMS & SERVICES

AT A GLANCE

Medical Offices: 720-848-2080 | Medical Fax: 720-840-2106 | Nonprofit Offices: 303-788-4030

EDUCATION

☐ **MS 101 —** A free 2-hour class for the newly-diagnosed in a small-group setting that goes over the basics of MS, how our understanding of the disease has changed over the years, and how to maximize your wellbeing. To register for an upcoming class, please email education@mscenter.org or visit mscenter.org/ms101. Classes are held via Zoom.

☐ **Conversations on MS —** An informal town-hall style Q&A session where one of our neurologists will discuss MS news, research updates, symptom management, and other topics brought by attendees. Events may be either virtual or in-person around Colorado. For a schedule of upcoming sessions, visit mscenter.org/conversations.

☐ **Education Summits —** Presentations and discussions with leading minds in the care and treatment of MS. We present these half-day events twice a year — spring and fall — free of charge to all attendees. Join us live in the Denver area, or watch the livestream from home. For information and schedules, please visit mscenter.org/edsummit.

☐ **Webinars —** Our webinar series features presentations on timely and relevant topics to the MS community. Take a look at upcoming and archived webinars at mscenter.org/webinars.

☐ **InforMS Magazine and eMS News —** InforMS is our quarterly magazine, bringing you in-depth articles ranging from the science behind MS, to updates on the latest research in the field, to living with MS and related neurological diseases. eMS News is our monthly email newsletter featuring relevant updates and the latest news. Sign up for both at mscenter.org/subscribe.

☐ **MSCenter.org —** Visit mscenter.org to browse our website for more information on a variety of topics related to multiple sclerosis, including symptoms, treatments, general wellness and more. Also explore our evolving content on related neurological diseases and the growing field of neuroimmunology at mscenter.org/related-diseases.

To learn more or sign up for MS 101, scan below or visit MSCenter.org/ms101

To get our free publications, scan below or visit MSCenter.org/subscribe

SUPPORT

☐ **Hydrotherapy / Online Exercise Program —** Specialized MS aquatic therapy program designed to improve functional abilities typically offered two days per week at sites throughout the Denver area. We also provide Online Exercise Classes which are seated and adaptive strengthening and stretching workouts conducted via Zoom twice weekly. Contact Michele Harrison, PT at 720-273-7461, or visit mscenter.org/hydro.

☐ **Counseling and Referrals —** We are pleased to provide two free individual or family counseling sessions and referrals provided by a licensed clinical social worker. For an appointment, please call 303-788-4030 ext. 120.

☐ **Disability Assessment and Legal Assistance —** One-on-one education about Social Security Disability benefits, criteria and the application process. For more information or to schedule a free consultation please call 720-301-9708.

☐ **MS Young Professionals Network (MSYPN) —** MSYPN offers networking happy hours, education presentations, special fundraising events, volunteer opportunities and more for 21- to 40-year-olds with a personal connection to MS. Call 303-788-4030 ext. 111 or visit mscenter.org/msypn for more information.

CARE

☐ **RMMSC at CU —** Patients benefit from meticulous care provided by fellowship-trained neurologists, MS-specialized advanced practitioners, and an extensive team of experienced professionals. For appointments call 720-848-2080, ext. 4.

☐ **King Adult Day Enrichment Program (KADEP) —** Five days a week, our day program hosts adult clients at our facility in Westminster, providing therapeutic recreation activities, social contact, meals and wellness monitoring. KADEP is a home away from home for people with MS and other neurological diseases, as well as those living with brain injury and stroke. For more information call 303-433-6887.

RESEARCH

☐ **Clinical Research —** Our active MS clinical research program gives opportunities for patient participation in emerging therapies and treatments. Call 303-724-4644 for more information or visit mscenter.org/research.

☐ **RMMSC Tissue Bank —** Playing a vital role in finding a cause and cure for MS, the Tissue Bank acquires, processes, preserves and distributes post-mortem brain and spinal cord tissue for research. Call 303-788-4030 ext. 149 for more information. *If your call is concerning an urgent tissue bank donation, including the death of a donor, please call 720-626-6060.*

ROCKY MOUNTAIN MS CENTER

GUIDE

FOR NEW PATIENTS

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The Rocky Mountain MS Center Guide for New Patients is periodically updated.
Please visit MSCenter.org/guide to ensure you have the latest version and most up-to-date content.
This version was produced:

DECEMBER 2025

Rocky Mountain MS Center 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.

Rocky Mountain MS Center Guide for New Patients
is published by the Rocky Mountain MS Center (RMMSC). No part of this publication may be reproduced in any format without prior written consent from the publisher. All requests for permission to reprint must be made to publishing@mscenter.org.

The material presented in the Guide for New Patients is provided for informational purposes only and should not be considered a substitute for medical advice. We encourage patients to be informed about their condition and treatment options. Patients should always consult their own physician or medical team before altering or commencing any course of treatment. Some content is reviewed by clinical staff at the Rocky Mountain MS Center at University of Colorado.

NEW PATIENT CHECKLIST

This New Patient Checklist is designed to guide you through important steps to take as you begin your journey with us, ensuring you have all the resources and information you need from your first visit onward.

In this section, you will find a detailed list of tasks and items to complete prior to and following your next appointment. These steps will help us better understand your health history, answer your questions, and set a clear plan for your ongoing care. Our goal is to partner with you in managing your MS, empowering you to live your best life while receiving the most advanced and compassionate care available.

New Patient Checklist

THINGS TO SIGN UP FOR:

☐ Register for an upcoming MS 101 session: **MSCenter.org/ms101**

☐ Sign up for Rocky Mountain MS Center's eMS News electronic newsletter and our quarterly *InforMS Magazine*: **MSCenter.org/subscribe**

☐ If needed, other resources are available (social worker, support groups, therapy). Please talk to your care team if needed.

THINGS TO SCHEDULE:

☐ Follow-up Appointment with Neurologist (Date: ____________)

☐ Bloodwork if not done in clinic. If done externally, please obtain a copy of the results to provide to your neurologist or send a message when complete.

☐ MRI scans (Date: ____________)

- The number to call to schedule MRI scans at any UCHealth Location: (844) 723-2778
- If you get MRI scans done outside UCHealth:
    1. Please get a copy of your scan on a disc and bring it to your next visit.
    2. Please message your neurology team when you have gotten the MRI scans done. We do not automatically get notified when MRIs scans outside the UCH system are done.

BEFORE THE NEXT APPOINTMENT:

☐ Create a list of questions I have about MS, my treatment, my symptoms etc.

- ____
- ____
- ____
- ____
- ____
- ____

I HAVE REFERRALS TO SEE…

- **NAME:** ____________________ **PHONE:** ____________________

  OFFICE: ____________________ **SPECIALTY:** ____________________
- **NAME:** ____________________ **PHONE:** ____________________

  OFFICE: ____________________ **SPECIALTY:** ____________________
- **NAME:** ____________________ **PHONE:** ____________________

  OFFICE: ____________________ **SPECIALTY:** ____________________

Notes

IF YOU'RE STARTING AN ORAL / INJECTABLE MEDICATION:

☐ **Step One:** Fill out the start form for that medication if needed

☐ **Step Two:** Sign up for copay assistance programs if you have commercial insurance. You can do this through the company that produces your DMT. Call the MS Center at CU for assistance if you aren't sure where to get started with this process (720-848-2080).

- Please always let your neurologist know if your out-of-pocket costs are unreasonable

☐ **Step Three:** Make sure to mark down on your calendar when you need to request refills

- Your neurology team will always order three month supplies of medications but sometimes only one month will be given at time by insurance.

☐ **Step Four:** Determine what strategy you will use to help you remember to take your medication on time. It is very important that you adhere to your medication schedule as directed. You may need to set reminders on your phone, mark the dates on your calendar, or find another strategy that will work for your lifestyle.

IF YOU'RE STARTING AN INFUSION MEDICATION:

☐ **Step One:** Fill out the start form for that medication if needed.

☐ **Step Two:** Find an in-network outpatient infusion center close to home and let your doctor know the name of it. Your doctor cannot order the infusion unless there is a location identified.

- You can find what is in-network by calling the phone number on the back of your insurance card. Some drug companies also have liaisons that can help you find a location in network (they will reach out to you if you have given them permission to do so; this is usually a checkbox on the start form)
- If you identified multiple infusion centers, you can let us know and we can help you pick one.
- Most insurances will not cover infusions at UCHealth because it is considered a hospital-based infusion center and they prefer outpatient infusion centers.

☐ **Step Three:** Sign up for copay assistance programs if you have commercial insurance. You can do this through the company that produces your DMT. Call the MS Center at CU for assistance if you aren't sure where to get started with this process (720-848-2080).

- Please always let your neurologist know if your out-of-pocket costs are unreasonable

☐ **Step Four:** If you hear about a denial, please let us know. You may hear about denials sooner than your doctor's office gets notified.

- A denial may require an appeal. Depending on where your infusion will happen, either the infusion center or your neurologist's office will submit an appeal. There is often a lag period for insurance companies to review appeals and make decisions.

☐ **Step Five:** Once approved, schedule your infusion at the infusion center.

YOUR EXPERIENCE GOING FORWARD

As you start your care journey, we know you'll have questions about what to expect and how things will unfold. This section is here to answer some of the most common questions, so you feel more comfortable and prepared moving forward. We want you to feel supported and informed every step of the way.

Below, you'll find answers to important questions about your care, from how appointments work to what kind of support is available. While every MS journey is different, these answers will give you a better idea of what's ahead and how we're here to help.

Frequently Asked Questions

Q: HOW OFTEN DO I SEE MY NEUROLOGIST AND WHY?

A: You will see your neurology team at least twice a year (every 6 months) — this may be visits with either your neurologist, or an MS-specialist Advanced Practice Provider (APP). There may be more frequent appointments if there are multiple medication changes being made, if there are side effects or if other urgent issues come up. Most of the medications we use in our clinic need regular monitoring at least every 6 months and can carry harmful effects if not appropriately monitored.

The initial visit in clinic is 60 minutes but subsequent visits are 30 minutes. Please make sure to arrive on time so we can optimize visits! If you arrive late, we will try our best to see you but it may be a shortened visit.

Q: IS THERE AN OPTION FOR TELEHEALTH VISITS?

A: We can do telehealth visits. These can be done as one of your twice a year visits. You must be in the state of Colorado to do a telehealth visit. Telehealth visits are done through the My Health Connection website and phone app.

Q: FREQUENCY OF BLOODWORK

A: For most disease modifying therapies (DMT), bloodwork is required every six months. If you are getting an infusion therapy, it is often possible to get bloodwork on the same day as your infusion. If you do not get bloodwork done with your infusion, it is important to get bloodwork no more than two weeks before your next infusion; one of the blood tests is not helpful to have done after the infusion.

Q: FREQUENCY OF MRI SCANS

A: MRI scans are done at least annually in the first few years after diagnosis. We do MRI scans without contrast for surveillance imaging and we are still able to see if there are new lesions. We only need contrast if there are active lesions. We generally do annual brain imaging. If you have spinal cord lesions, we may do these on a semi-regular basis as well (this will vary depending on your neurologist and symptoms). Lumbar spine imaging is not typically done in our clinic as multiple sclerosis does not affect the lumbar spine (lower back). Later, you may have MRIs spaced out to every other year, every three years, or longer.

Q: DO I NEED TO KEEP SEEING MY PRIMARY CARE PROVIDER?

A: Yes absolutely! Your neurologist is really focused on your multiple sclerosis and it is important to make sure your primary care doctor is still doing age-appropriate

medical screening and testing. If other health conditions are not properly treated (high blood pressure, high cholesterol, diabetes etc), it could make MS worse.

Q: WHAT IS UCHEALTH'S 'MY HEALTH CONNECTION' & HOW DO I SIGN UP FOR IT?

A: My Health Connection is the patient portal for our clinic. It should be used for things that can't wait until your next appointment (medication issues, new neurologic symptoms). All patient messages will initially go to our team of trained MS nurses and will be forwarded to your physician or nurse practitioner if further guidance is needed.

Please know messages will be answered in 48–72 hours. If there is an emergency, please go to the emergency department.

During your initial appointment, if you do not already have a MyHealthConnection login, you will be provided with a code to sign up. You can download this app on your smartphone through the app store or can go to **UCHealth.org/access-my-health-connection/** to access on your computer.

Q: WHAT DO I NEED TO BRING TO MY VISITS?

A: Bring in a list of any medications and/or supplements that you are taking (include dose and who prescribed it), the discs from any MRIs you've had done outside the UCH system since your last visit, a copy of lab results done outside the UCH system since your last visit, the questions you have for your neurology team, a list of symptoms you're experiencing, a notebook to jot down information, and consider bringing a support partner to be a second set of ears.

Notes

ABOUT MULTIPLE SCLEROSIS

Learning about MS can feel overwhelming at first, but understanding what's happening in your body is an important part of managing the condition. The Rocky Mountain MS Center has spent years crafting, curating, revising and updating the most current information on MS. Through our various education programs — including this booklet — we aim to ensure that patients are informed and empowered through understanding the disease.

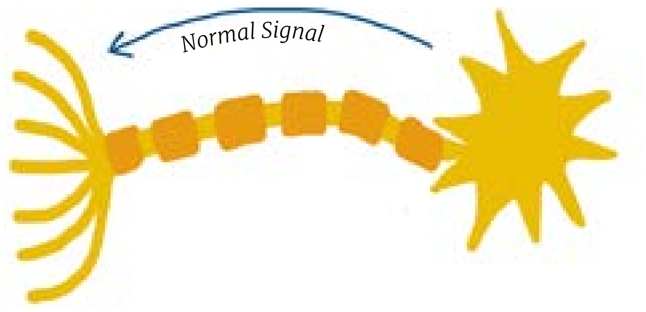
This section will give you a clear, simple explanation of MS and help you understand what might be happening in your body, as well as what can be done to manage the condition moving forward.

Our understanding about MS and the ability to treat it has evolved dramatically over the past 30 years. Prior to 1993, there were no approved therapies for MS. Today, there are **more than 20** approved disease modifying therapies (DMTs) to treat MS and several more in development.

What does this mean for someone that is newly diagnosed? It means that there is hope for slowing down or stopping new disease activity after diagnosis!

Our goals are to allow all our patients to be able to do what they desire for as long as they desire to do it. We work very closely with our patients through shared decision making to accomplish that as best as we can. Both the Rocky Mountain MS Center (nonprofit) and the Rocky Mountain MS Center at the University of Colorado (clinic) advocate for patients to maximize lifelong brain health through early and effective treatment and adoption of a healthy lifestyle.

1. Normal Neuron



2. Demyelinated Neuron

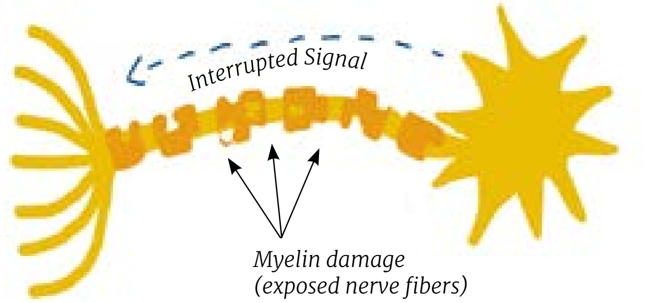


***Fig. 1** – This represents a normal neuron, or nerve cell. There are areas of myelin (in orange) throughout the long portion of the nerve cell, called the axon (in yellow). This is what helps with optimal signal transmission. You can think about nerve cells as being similar to wires. The axon is the wires itself and the myelin is the insulation.*

***Fig. 2** – This is what a demyelinated neuron, such as those affected in MS, looks like. In MS, we can see damage primarily to the myelin (or insulation) but the axon can also be affected (or central wires). This causes a disruption in nerve signal transmission.*

MS: THE BASICS

Multiple Sclerosis is an autoimmune disease that affects the brain and spine. An autoimmune disease happens when your immune system, the system that typically helps us fight infections, gets "misprogrammed" and begins to attack your body instead. Other autoimmune diseases that you may have heard of include rheumatoid arthritis, Hashimoto's (thyroid) Disease, and psoriasis.

In MS, your immune system attacks the nerves that are located within the brain and spine, which is called the central nervous system. The peripheral nervous system (the rest of the nerves in the body, such as nerve roots and peripheral nerves) are not affected directly by MS. When the central nervous system gets attacked, it can damage the communication between your brain and the rest of your body. This can cause interrupted or incomplete signals (see figures 1 and 2). The severity of the disease and its symptoms vary from person to person, largely related to lesion location and degree of recovery from lesions. Most lesions, especially in the brain, do not cause symptoms — lesions that show up on MRI scans may not always align with the number or severity of symptoms someone experiences.

Although there are treatments that can slow disease progression, at this time there is no known cure. There have been several studies looking at the impact of diet and exercise in MS. Unfortunately, there is no one diet or exercise regimen that can stop MS activity on its own. However, in combination with the appropriate MS medication (DMT), a proper diet and exercise regimen can help optimize how well someone with MS does.

WHAT ARE THE SYMPTOMS OF MS?

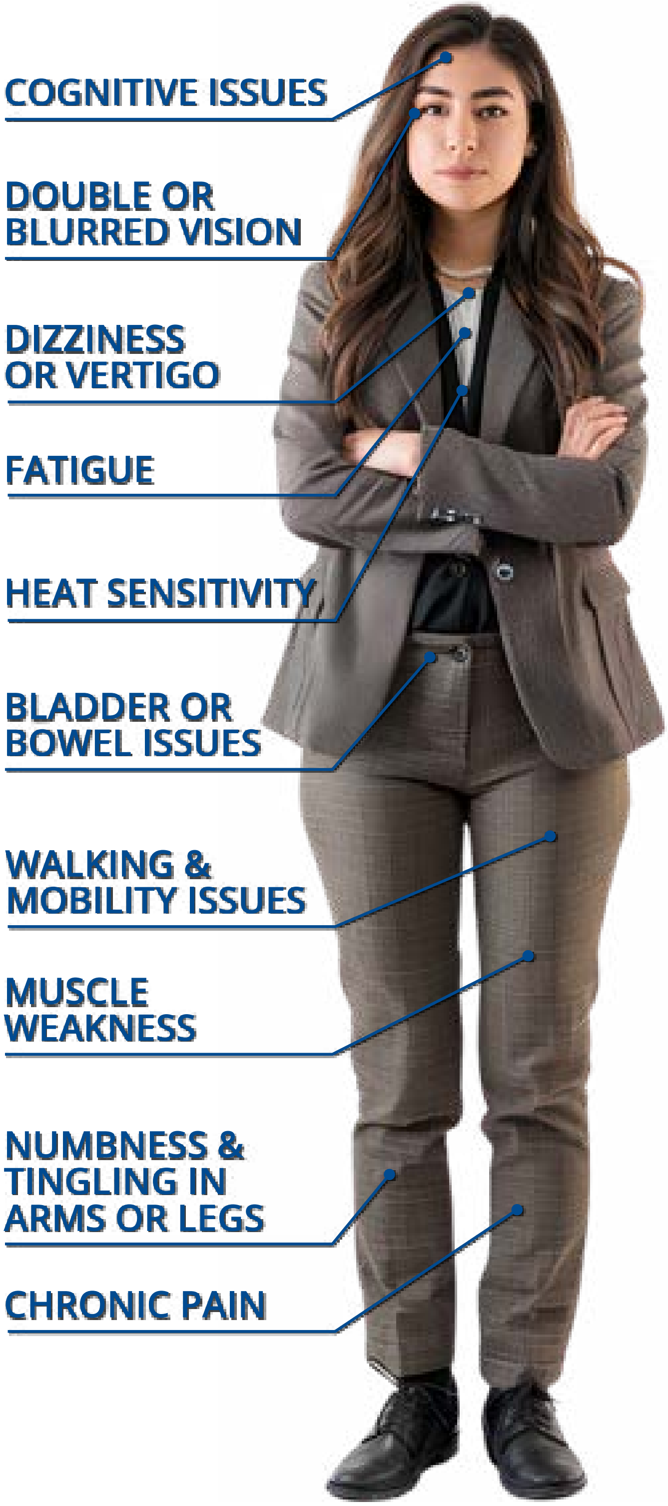
Symptoms are caused by areas of myelin and nerve damage known as lesions. Symptoms are typically more pronounced when they first develop due to significant inflammation and recover to some degree over time. While symptoms may improve or resolve, once a lesion forms, it tends to stay throughout one's lifetime and can be seen on MRI scans.

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. It's a disease that looks different for every individual – yet it has some common elements.

Common MS symptoms can include both visible and invisible symptoms. This means some can be seen by others while some may just be felt by the patient. It is important to keep in mind that you likely won't experience every one of these symptoms. Most patients experience some combination of symptoms, but it is rare to experience them all. Some of the most common symptoms possible include:

- **Weakness**
- **Sensation Abnormalities (numbness, tingling)**
- **Coordination Issues**
- **Vision Issues (double vision, loss of vision)**
- **Bowel and Bladder Problems**
- **Trouble with Walking / Imbalance**
- **Cognition**
- **Dizziness and Vertigo**

DO YOU *SEE MS*?



SEE MS

Sparking Education and Empowerment in MS (SEE-MS) is an early-awareness campaign by the Rocky Mountain MS Center. For more information, visit us at **MSCenter.org/seems**.

- **MS Hug**
- **Spasticity and Stiffness**

Some symptoms are common in MS but can also be caused by many other conditions.

- **Mood Disorders & Depression**
- **Dizziness and Vertigo**
- **Fatigue**
- **Heat Insensitivity**
- **Pain**
- **Problems Swallowing**
- **Sexual Problems**
- **Sleep Disorders**

Please see pages 31-40 for more information about individual symptoms.

MS typically tends to go through both quiet and active periods. Active periods tend to have new lesion and symptom formation, known as relapses or exacerbations. During exacerbations, symptoms can be more pronounced, but may subside and sometimes go away entirely after an exacerbation. During the quiet periods, while there may not be **new** symptoms, many patients may still be coping with symptoms leftover from prior relapses as above or other invisible symptoms.

Some symptoms, like fatigue or pain, may linger but vary in their severity from day to day. Other patients may not experience dormant periods, and instead live with constant symptoms or a progressive worsening of the disease. Every case of MS is different, and every patient's experience is unique. 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.

No person experiences the same symptoms in the same way, making MS a particularly difficult experience to explain or relate to others.

MS 101

MS 101 is a free 2-hour class for the newly-diagnosed (anyone who has been diagnosed in the last 5 years) in a small-group setting and conducted via Zoom. We encourage you to bring family, friends, care partners, and anyone else who may benefit from learning more about MS with you.

DIAGNOSING MS

The diagnostic criteria has changed over time to allow for quicker diagnosis and the ability to treat earlier.

Despite the many advancements in our understanding of MS, there's still no single symptom, or clinical observation, or laboratory test that can determine if you have it. Early symptoms, initial doctor visits, and observations and tests are all pieces of the puzzle that have to be put together.

Neurologists often like to say time is brain. Identifying MS as early as possible and beginning the most appropriate and effective treatment for each patient can fundamentally change how their disease progresses over time.

WHAT IS AN MRI AND HOW IS IT USED IN MS?

MRIs are the most used tools for diagnosis and monitoring. MRIs can show both active lesions (when contrast is used) and past MS activity. MRIs show where lesions are. Often, the location of lesions can be more important than the number of lesions you may have. Think about your brain as a road map and all of your nerve fibers are roads. You will have county roads without much traffic (nerve signals), busy superhighways

with many lanes and tons of traffic, and complicated intersections. If there is damage to a road (MS activity or lesions), the level of impact (symptoms) felt will depend on how much traffic is using that road. So, a pothole or lesion on a county road will cause less inconvenience (symptoms) than damage to the superhighway which will cause major concerns.

Ninety percent of lesions in the brain and thirty percent of lesions in the spinal cord can be asymptomatic, meaning that in untreated MS you may continue to accumulate damage even when you are not experiencing symptoms. This is why it's important to get regular MRIs, follow the advice of your neurologist, and take your medications as prescribed.

WHO GETS MS AND WHY:

MS is most commonly diagnosed in young adults. Eighty percent of MS patients develop MS between the ages of 16 and 45, however, individuals may be diagnosed earlier or later in life. Women are 2–3 times more likely to be diagnosed with MS compared to men. According to a study in 2019 published in the journal Neurology, nearly 1 million adults in the United States have MS. Based on the study's estimates, approximately 16,000 Coloradans are living with MS, or an estimated one in 360 people. MS is not a disease that requires reporting so it is very possible that the actual numbers are higher than these estimates.

While we don't know the exact cause, three factors appear to have an influence on developing MS: genetic predisposition, environmental factors, and a trigger, such as a virus. There are factors associated with increased risk of MS development including low vitamin D levels, tobacco use or exposure, history of having the Ebstein-Barr Virus (also known as the virus that causes mono or the kissing disease), childhood or adolescent obesity, family history of MS or other autoimmune conditions.

We do know that MS is not a traditional hereditary disease and there is no one gene responsible for causing MS. Over 200 genes have been identified as potential risk factors for MS and there is quite a bit of research being done in this area to understand genetic susceptibility to MS.

There has to be a "perfect storm" for one to get diagnosed with MS. You can have one or all of these risk factors and it doesn't necessarily mean that you will develop MS.

Webinar: Understanding MS

This one-hour webinar is designed to be a tool that people with MS can use to help explain their experiences to people who don't have MS. Learn from our MS 101 presenters — Elissa Berlinger, LCSW, and Kelsey Morrow, the MS Center's Education Manager.

Notes

RECOGNIZING AN MS RELAPSE

Recognizing an MS relapse is an important part of managing your condition. A relapse — sometimes called a flare-up, attack, or exacerbation — happens when new symptoms appear or existing ones suddenly get worse. These changes can last for days, weeks, or even months. Understanding what a relapse looks like can help you respond more quickly and get the treatment you need.

In this section, we'll go over common signs of a relapse, and learn how to tell the difference between a true relapse and temporary symptom changes caused by other factors like stress or illness. Knowing the difference will help you feel more in control and know when it's time to reach out to your healthcare team.

WHAT IS AN MS RELAPSE?

MS causes damage from inflammation in the CNS (brain and spine). While MS impacts the CNS in various ways, one of the main targets is the myelin, a protective sheath that wraps around normal nerve fibers and helps ensure they can conduct nerve impulses efficiently.

When that myelin is damaged, the nerve impulse is slowed or even completely blocked, resulting in a variety of different symptoms. When these symptoms occur for the first time — the initial attack on that specific area of the nervous system —we call it a relapse.

The following is general criteria needed to meet to classify an event as an MS relapse:

- **New neurologic symptoms (these are symptoms you have not had before and not typically just worsening of symptoms you have had in the past);**
- **Symptoms last more than 24 hours;**
- **Symptoms develop over minutes to hours; and**
- **There is a new lesion seen on the MRI scan that would explain those symptoms**

The key point to understand is that a relapse is new MS activity, as measured not only by symptoms, but also by exam and the presence of new MRI lesions. New MS attacks may occur in any MS patient but are most common when people are younger and/or relatively more newly diagnosed.

MS RELAPSE SYMPTOMS

When we think of MS relapses, they tend to follow a specific pattern or affect a particular part of the Central Nervous System (CNS). Several examples of relapses include:

- **Vision symptoms**
  - **Optic Neuritis: Inflammation in the optic nerve (the nerve leading from the brain to the eye). Symptoms usually include blurry vision that is typically in one eye but can rarely be in both eyes. The blurry vision does not get better with glasses. There is often pain or soreness with eye movements and a change in the vibrancy of the color red.**
  - Diplopia (double vision): this typically causes persistent and ongoing double vision, which can sometimes be worse when looking in a particular direction.
- **Sensation symptoms**
  - Numbness and/or tingling in one limb or half of the body
  - Lhermitte's: a vibration or shock-like sensation from the neck down when you bend your neck forward
- **Weakness**
  - Weakness in one limb or half the body
- **Balance issues**
  - Challenges with balance or coordination
- **Vertigo**
  - Persistent feeling of the world spinning around you. Typically vertigo in MS doesn't cause dizziness that only lasts a few seconds or minutes (in those cases, we think about the inner ear or another cause)

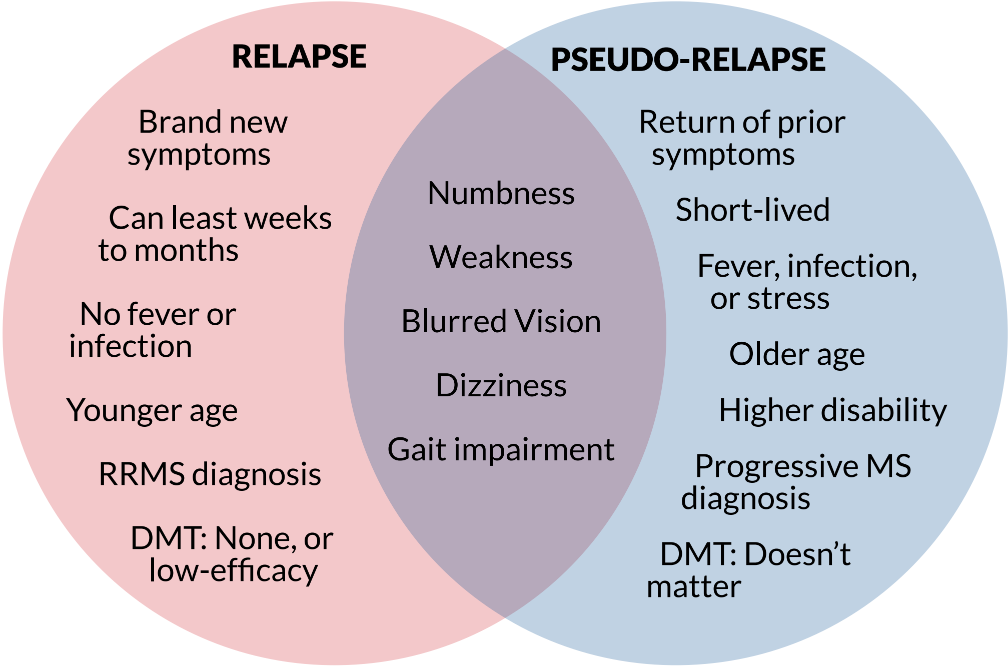
PSEUDO-RELAPSES (Recrudescence)

What exactly is an MS relapse, and what's the difference between a true relapse and a pseudo-relapse?

After a relapse, our neurologic reserve comes into play, helping our nervous system to avoid or bypass areas of damage. There is

Relapse or Pseudo-Relapse?

Listed in the red area are common indications of an MS Relapse. In blue are symtoms that are commonly associated with a Pseudo-relapse. And in purple, symptoms that may be present in either case. It's important to note that this graphic reflects the most common patient experiences, and any of these symptoms have the potential to occur in either a true MS Relapse or a Psuedo-relapse.



also some healing that our brains are able to do in areas of previous lesions.

However, it is really important to understand that, even if our symptoms from the relapse have gone away, those lesions still exist. Your brain has just found a way to re-route around those lesions. This means that, in situations where there is increased stress put on the neurologic system, you may start experiencing those old symptoms again.

Think about your brain pathways being like highways and local roads. If there is construction on the highway, you will have a backup of traffic and this will cause significant delay (similar to a lesion causing symptoms). In ideal situations, cars will be able to take local roads and there won't be significant delay (similar to your brain re-routing the signals). However, if there are stressors on the system, such as rush hour, you will again have backup of traffic and symptoms of delay again.

In MS, those things that cause stressors in the system can be quite varied from person to person. But we know we can see recurrence of symptoms, also known as recrudescence or pseudo flares, in any situation that increases body temperature by ¼ of a degree.

Pseudo-relapses can trigger some or all of the same symptoms that a prior relapse may have caused. This can make them nearly indistinguishable from a true MS relapse. And, of course, when you're in the midst of experiencing symptoms, whether it's a true relapse or a pseudo-relapse, doesn't really matter to you — your symptoms are very real, regardless of what's causing them. It is very important to note that pseudo-relapses can be helped by treating the underlying cause.

However, it is important to understand the difference, so we can better determine the next steps in treating whichever possibility is happening with you.

A true relapse indicates new inflammatory activity in the brain and spine and may indicate a need to reconsider your current disease modifying therapy regimen.

A pseudo flare does not indicate new inflammatory activity and is just a reminder of lesions from the past; this does not typically require steroids or a change in disease modifying therapy.

ARE YOU HAVING A RELAPSE OR PSEUDO-RELAPSE?

The difference between a true MS relapse and a pseudo-relapse may not be immediately evident to you, and that can be a concern because treating the two possibilities can look very different.

A quick sidenote: Few people are particularly satisfied with the term “pseudo” relapse, as it indicates something that’s not real. You may hear medical professionals call it “recrudescence.” Whatever the terminology, a pseudo-relapse is VERY real, as anyone who’s experienced one can tell you. It’s just not indicative of new or worsening MS activity that tells us there is **new** inflammation or **new** MRI changes.

This is especially true if the symptoms are very similar to what you’ve experienced during a previous relapse. Slight changes in location or increases in severity can be a sign of new MS activity occurring near existing lesions. For example, a prior attack may have caused numbness in your hand, and the new event is numbness in the same hand but also now extending up your arm to the shoulder.

If your symptoms are similar to a previous relapse, that’s a good indication that you may be experiencing a pseudo-relapse. Most relapses occur in new parts of the nervous system, so when you have the same or very similar fluctuation of symptoms over and over these are almost always pseudo-relapses. Pseudo-relapses also commonly clear up quicker than true relapses, especially when and if the contributing factors associated with the recurrence of the old symptoms are resolved quickly. They may be quite severe, especially if someone had a severe attack from which they previously recovered.

There are a number of factors not directly related to MS that are known to contribute to pseudo-relapses. Some of these factors may include:

- **Infection, even simple ones like upper respiratory symptoms such as cough, urinary tract infection, sneezing, etc.**
- **Fever**
- **Overheating (can be from both external, such as hot temperatures, and internal, such as increased body temperature from exercise, causes)**
- **Physical or emotional stress**
- **Changes to other medications you may be taking, possibly prescribed by another physician and for reasons unrelated to MS**

Conversely, new symptoms you haven’t had before, or symptoms that are significantly worse than what you’ve previously experienced but in a similar location, can be indicators that new MS activity is underway — a true MS relapse.

Thankfully, there are several diagnostic strategies to help your MS care team determine if you’re having a relapse or a pseudo-relapse.

New relapses and pseudo-relapses may be extremely difficult to distinguish. In some cases your doctor will want to do a relapse history, perform a neurological exam, and order one or more MRI scans looking for new MS lesions, or evidence of new MS activity in the area of existing lesions. MS activity visible on an MRI is the most definitive way to determine if you’re experiencing a true MS relapse, but it is the constellation of history, exam and MRI together that is most helpful.

If you’re experiencing symptoms that seem related to your MS and you have any question as to whether you may be having an MS relapse or pseudo-relapse, it is very important to contact your MS care team right away so they can help you determine the best course of treatment for what you’re dealing with.

PROGRESSION & DIFFERENT ‘TYPES’ OF MS

MS doesn’t look the same for everyone. Understanding how it manifests and progresses can help you and your care team make better decisions about managing your symptoms and planning treatment.

In this section, we’ll look at progression, break down the main “types” of MS, and explain why categorizing MS into these types can be helpful — even if the distinction between them is the subject of some debate. Knowing the differences can give you clearer expectations and a sense of what your care plan might look like moving forward.

MS PROGRESSION

The accumulation of disability in MS can occur for a number of reasons including relapses which tend to occur over hours and days and are accompanied by new MRI findings.

Progression refers to a steady accumulation of disability over time directly related to MS, occurring slowly over months and years. For many people with MS, especially those with progressive forms of the disease, this can mean subtle changes like increased fatigue, slower walking, or difficulty with daily tasks.

Worsening is a broader term that includes both progression and relapses, as well as things not related to MS such as aging, deconditioning, or other medical conditions. While worsening can sometimes improve with treatment or resolve over time, progression tends to reflect a more gradual and irreversible decline in function.

One of the challenges with MS progression is that it often unfolds slowly and can be difficult to distinguish from the natural effects of aging. Symptoms such as stiffness, balance issues, or cognitive changes may emerge gradually, making it hard to tell whether they are due to MS or simply getting older.

Unfortunately, current MS treatments are most effective against inflammatory relapses and have limited benefit in halting or reversing progression. However, ongoing research is exploring new therapeutic targets, including those aimed at neuroprotection and remyelination. Scientists are also working to better understand the biological mechanisms behind progression, with the hope of developing more effective treatments in the near future.

DIFFERENT "TYPES" OF MS

In the past, MS was commonly divided into four separate forms or "types" of the disease. Today we think of MS as one disease, with different symptoms from person to person, but also changing manifestations over the course of the lifetime of a single patient.

There is still debate as to how distinct or different these forms of MS are from each other, but it's nonetheless useful to look at these four categories as a way to explain how MS manifests at different stages in different people. You may see your neurologist refer to particular types of MS in their clinical documentation; this is often something required by insurance companies to help with approval of particular medications.

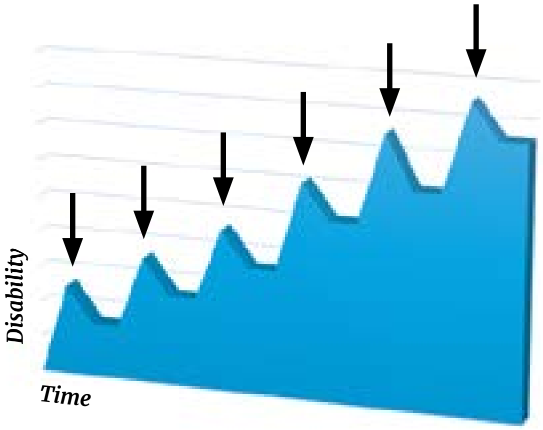
CLINICALLY- AND RADIOLOGICALLY-ISOLATED SYNDROME

Clinically Isolated Syndrome (CIS) refers to essentially the earliest signs of the disease, or the first relapse. If a person never experiences another exacerbation, or their MS does not progress or get worse over time, this singular event is said to be CIS. Most patients however will eventually experience another exacerbation, in which case they fulfill criteria for a formal diagnosis of MS.

Most patients have MS for likely years before they are diagnosed as we can often see lesions on MRI that are no longer active when they are diagnosed. In some patients, they can be diagnosed with **Radiologically Isolated Syndrome (RIS)** if they get an MRI before they develop symptoms of MS for example to evaluate headaches or are participating in a research study. There is now evidence that treating this early stage can sometimes be helpful.

RELAPSING-REMITTING MS

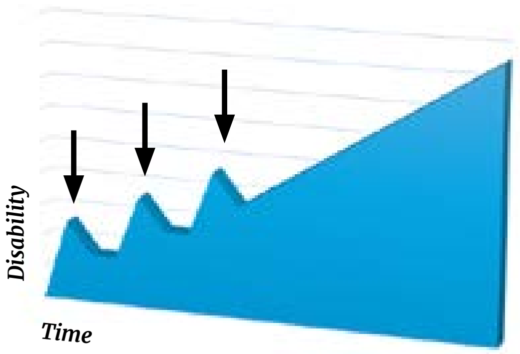
Relapsing-Remitting MS (RRMS) is diagnosed in someone when they have a second attack and/or new changes on MRIs over time. Some people can be diagnosed with RRMS on their first visit if they meet certain criteria with history, MRI scans and with spinal fluid analysis. For most patients with RRMS, relapses and new MRI changes are most common when they are younger, and risk of new relapses diminishes with age.



Each peak/arrow represents a relapse.

SECONDARY PROGRESSIVE MS

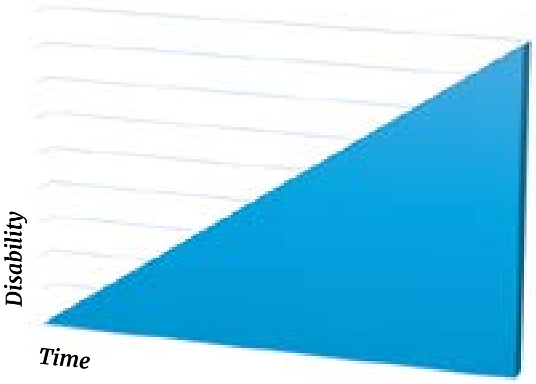
Secondary Progressive MS (SPMS) is when there is slow worsening of symptoms over time in place of active relapses and new symptoms. This may be manifested especially with greater walking and cognitive problems and is called SPMS. Men, and especially those with very active relapses when first diagnosed, are at higher risk of developing SPMS.



Each peak/arrow represents a relapse.

PRIMARY PROGRESSIVE MS

Primary Progressive MS (PPMS) is diagnosed when someone has a steady progression of MS symptoms that is not preceded by relapses. Average age of onset is similar to those with SPMS, about 40–45 years old. Followed long enough, a minority of those with PPMS could have a relapse.



Notes

TREATMENT OF MS

When it comes to managing MS, treatment options have come a long way in recent years. While there's no cure, there are a variety of treatments available that can help slow the progression of the disease, manage symptoms, and improve your quality of life. From medications to physical therapies and lifestyle changes, finding the right combination for you is key.

In this section, we'll explore the MS Center's treatment philosophy and why we believe early treatment with the most effective therapies available is the best path forward for most patients. We'll also look into Disease Modifying Therapies (DMTs), the pharmaceutical treatments available to help you manage your MS.

The following represents the logic for why we at the Rocky Mountain MS Center at University of Colorado suggest early and aggressive treatment with disease modifying therapies for MS:

1. **MS is a challenging and unpredictable disease.** It most likely represents both inflammation (the immune system attacking the nervous system) and neurodegeneration (the loss of brain cells) over time. Many patients will develop some disability, however, and this can have important effects on walking, mental processes, employability, and ability to function in the work and home environment.
2. **The inflammatory component of MS tends to be most important early in the course of the illness, although it likely persists for many years.** Inflammation appears as new relapses and new, especially "active", MRI lesions in the brain and spine. The presently-available disease modifying therapies (DMTs) primarily target the inflammatory component of MS.
3. **New inflammation (relapses or imaging changes) can cause symptoms in the short term.** However, we can also **see long term effects from ongoing inflammation, including impacts on walking and cognition as well as loss of brain volume.**

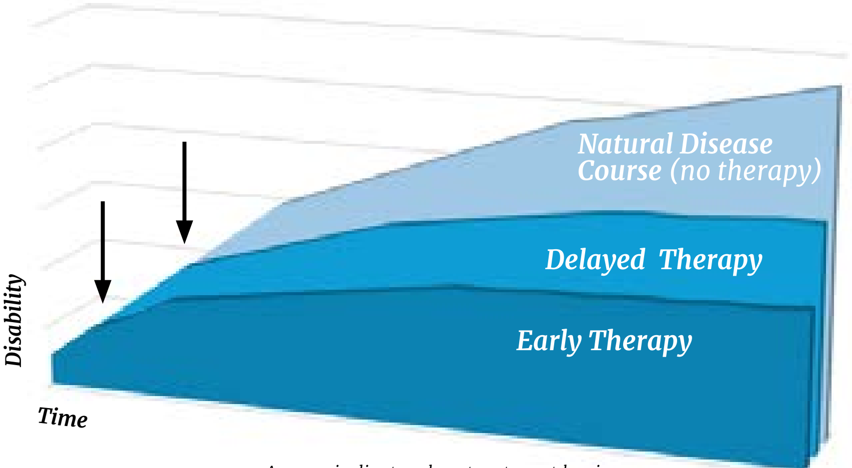
Thus, maximal suppression of new inflammation early in the course of the illness offers the greatest opportunity to limit the effects of the disease. In general, in our practice, this means very little use of the older, self-injectable medications (also known as "platform therapies"), and much higher use of newer, oral and IV medications. It also means offering research opportunities, and sometimes using medications "off-label", that is, using drugs that are approved for conditions other than MS, but which are known to be quite useful in MS.

There are now more than 20 unique FDA-approved MS DMTs, including multiple generics, and Rituximab is also used "off-label" frequently for MS. Choosing the one that is best for any single person is a process unique to that person and based on many factors, including effectiveness of the drug, potential short-term side effects, potential long-term risks, family planning considerations (pregnancy, breastfeeding), cost/insurance issues, and patient and doctor preferences. But our belief, based on published studies and many years of personal experience, is that early and aggressive therapy with the DMT that allows for maximal suppression of inflammation with acceptable risk for that patient gives the patient and their family the greatest likelihood of living a long and productive life together. For the patient and their family, to get to the best choice for them, this means reading about the various options and asking us any and all questions they have about the options.

Over time, as MS changes, there may be consideration to de-escalate the intensity of therapy, and perhaps lower risks, and even to possibly discontinue the use of some drugs in older patients who are no longer having active new attacks or relapses of their MS.

Of note, please make sure you are looking at reputable websites when reading more about these medications. Examples include the Rocky Mountain MS Center, National MS Society, Multiple Sclerosis Foundation and Multiple Sclerosis Association of America. While social media sites (Facebook, reddit, etc.) can be incredibly helpful, it is important to note that not everyone's experiences are the same. Similar to any product reviews, individuals are most likely to comment if they have had a negative experience as opposed to a positive

Why Treat Early?



Arrows indicate when treatment begins.

This chart illustrates the typical course of MS among those who treat early, those who delay treatment, and those who don't receive treatment at all.

one; this can cause a skewed and inaccurate impression. If you have questions about something you read, please bring those to your neurologist as part of the treatment discussion.

Disease Modifying Therapies

Multiple sclerosis medications are commonly called **Disease Modifying Therapies (DMTs)**, mostly working to change the course and progression of the disease rather than cure it. The first of these was introduced in the early 1990s, and the list of approved medications has been growing ever since.

Individualizing treatment according to a patient's risk profile starting with high-efficacy treatments helps prevent irreversible brain and spinal cord damage, thus leading to better outcomes.

The neurology team at the Rocky Mountain MS Center generally categorize today's many DMTs as follows:

HIGH EFFICACY THERAPY

- **Ocrelizumab** (Ocrevus and Ocrevus Zunovo), **ofatumumab** (Kesimpta), **ublituximab** (Briumvi), and **rituximab** (Rituxan is used off-label), **Natalizumab** (Tysabri) *(NOTE: Natalizumab is a First Line treatment ONLY for JCV-negative patients)*
- **Alemtuzumab** (Lemtrada) *(NOTE: not often used in modern day treatments due to high incidence of side effects)*

MODERATE EFFICACY THERAPY

- **Fingolimod** (Gilenya), **siponimod** (Mayzent), **ozanimod** (Zeposia)**,** **ponesimod** (Ponvory)
- **Dimethyl fumarate** (Tecfidera), **monomethyl fumarate** (Bafiertam), **diroximel fumerate** (Vumerity)
- **Cladribine** (Mavenclad)

PLATFORM THERAPIES

- **Teriflunomide** (Aubagio)
- **Glatiramer acetate** (Copaxone, Glatopa, generic GA)
- **Beta interferons** (Avonex, Rebif, Betaseron, and others)

Disease Modifying Therapies in MS

Class	Drug Names *(brand and generic names)*	Route of Administration & Dosing Info	Mechanism of Action	Characterization of Efficacy	Possible Side Effects
Interferons	Includes Betaseron®; Avonex®; Plegridy®; Rebif®; and Extavia®	Injection (subcutaneous or intramuscular). All are injected and differ by dose and frequency of injection.	Changes activation of lymphocytes.	Low	Depression, suicide, psychosis, liver toxicity, seizures, allergic reactions, congestive heart failure, decrease peripheral blood counts, thrombotic microangiopathy, flu-like symptoms common (49%).
Glatiramer Acetate	Copaxone® daily; Copaxone 3x/wk; Glatopa® daily; Mylan®3x/wk	Injection (subcutaneous). All injected under the skin by the patient and differ by dose and frequency of injection.	Works by inducing a regulatory B cell or T cell specific for MS.	Low	Post-injection reaction (16%), transient chest pain (13%), lipoatrophy (localized loss of fat tissue), skin necrosis, injection-site reactions.
Teriflunomide	Aubagio®	Oral. Taken once a day.	Inhibits the ability of all lymphocytes to multiply, leads to lymphocyte death including B lymphocytes.	Moderate	Boxed warning* for hepatotoxicity (including fatal liver failure) and teratogenicity. low white blood cells ,risk of infection, peripheral neuropathy (1.4%-1.9%); elevated blood pressure (3%-4%); hair thinning.
Fumarates	Tecfidera®; Generic dimethyl fumarate; Diroximel fumurate (Vumerity®); Monomethyl fumarate (Bafiertam®)	Oral. Taken twice a day.	Inhibiting proinflammatory lymphocytes.	Moderate	Nausea, vomiting, abdominal pain/diarrhea, flushing, low lymphocyte counts, and rarely PML.
S1P Partial Agonist	Fingolimod; Gilenya®; Siponimod (Mayzent®); Ozanimod (Zeposia®); Tascenso ODT®	Oral. Taken once a day. Requires some specialized testing prior to starting depending on which medication is chosen	Retaining lymphocytes within lymph nodes	Moderate	First-dose bradycardia, risk of serious infection, PML***, macular edema, posterior reversible encephalopathy syndrome, liver toxicity, blood pressure, basal cell carcinoma, melanoma (2%). Only available through REMS**.
Cladribine	Mavenclad®	Oral. Taken as two cycles (one cycle is five days a month for two months)	Inhibits pro-inflammatory lymphocytes. Temporarily reduces the number of both T and B lymphocytes.	Moderate	Boxed warnings* for risk of cancers and birth defects if used in pregnant woman.
Alemtuzumab	Lemtrada®	Infusion. 5 days of IV infusion year 1 and 3 days IV infusion year 2.	Kills all cells expressing CD52 including B cells and T cells. Changes regulation of immune system.	High	Boxed warning* for serious (sometimes fatal) autoimmune conditions which occur in up to 40% such as immune thrombocytopenic purpura which is a bleeding disorder, life-threatening infusion reactions, risk of malignancies. Infusion reactions (92%), rash (53%), lymphopenia (99.9%). Only available through REMS**. Approved by FDA for rescue use only.
Natalizumab	Tysabri®	Infusion. Taken every 4-6 weeks	Blocks ability of activated lymphocytes to migrate into the brain.	High	Boxed warning for PML***. Risk for herpes encephalitis and meningitis, liver toxicity, hypersensitivity (including anaphylaxis) reaction. Only available through REMS**. Note: repeated negative testing for the JC virus that causes PML*** can dramatically minimize the risk of PML***.
CD20 Therapies	Ocrelizumab (Ocrevus®); Ocrevus Zunovo®); Ofatumumab (Kesimpta®); Ublituximab (Briumvi®); Rituximab (Rituxan®, Ruxience, Riabni)	Infusion (Ocrevus, Briumvi, Rituximab); Subcutaneous injection (Kesimpta); Subcutaneous infusion (Ocrevus Zunovo). Once every 6 month infusion with exception of Kesimpta, which is a once a month injection	Selectively depletes circulating B cells.	High	Infusion reactions, risk of infection, Hep B reactivation in Hep B positive patients, rare risk for PML***,

It is important to note that comparisons of effectiveness and impact on brain volume are not comparable to one another as the patient populations involved in these trials are very different. There are no head to head comparison trials between medications.

**** Boxed Warning:*** *A black boxed warning is the FDA's most stringent warning for drugs and medical devices on the market. Black box warnings, or boxed warnings, alert the public and health care providers to serious side effects, such as injury or death.*

***** REMS (Risk Evaluation and Mitigation Strategy):*** *REMS is a drug safety program that the U.S. Food and Drug Administration (FDA) can require for certain medications with serious safety concerns to help ensure the benefits of the medication outweigh its risks.*

****** PML (Progressive Multifocal Leukoencephalopathy):*** *PML is a rare but serious brain infection that is caused by the JC Virus (JCV). PML is seen in MS patients who are JC virus (JCV) positive and on disease modifying therapies known to increase the risk of PML. At least 50% of the general population has been exposed to JCV, but the infection is generally asymptomatic. But, in immunocompromised patients, including those taking certain MS DMTs, the JC Virus can infect the brain and result in PML. PML The first case of PML in MS was discovered in 2005 with the use of Tysabri.*

MS SYMPTOMS

Living with MS means that you may experience a range of symptoms, and it's important to know what they are. MS can affect almost any part of the body, leading to a wide variety of experiences that can change over time. Understanding these symptoms is key to managing your condition effectively.

In this section, we'll explore some of the most common symptoms of MS. Remember, everyone's experience with MS is unique, and different people may experience varying degrees of all, some, or none of these symptoms. It's important to pay attention to your own body and seek support when needed.

MS symptoms develop when the immune system mistakenly attacks and damages the protective covering of nerve fibers, called myelin, and/or the nerves themselves. These damaged areas disrupt the normal flow of electrical impulses through the nervous system. Exactly where this damage forms in the brain, spinal cord, and optic nerve can be completely different from one person to the next, and the location impacts the symptoms a person experiences. Due to this fact, MS symptoms can vary widely among individuals, and not everyone will experience the same set of symptoms or the same severity of those symptoms.

There's also no guarantee that an individual diagnosed with MS will exhibit any or all of the listed symptoms. Please join us at **MSCenter.org/symptoms** for a longer list of potential MS symptoms, and much more information and resources.

FATIGUE

Fatigue is the most common MS symptom and, along with pain, is the most frustrating for people to manage. It's unpredictable and invisible and is often misattributed, not to the MS disease process, but to denial, disinterest, self-pity, disorganization, poor planning, or just plain laziness. As many as 90 percent of people with MS have fatigue --probably half of them experience it every day. One third of people with MS describe it as their most troublesome symptom

Fatigue is a frequent cause of disability. Fatigue is difficult to define because it's a collection of different symptoms that vary in frequency and intensity. Although fatigue is a big problem, it's a slightly different problem for each person who has it, so it's difficult to measure and therefore difficult to study.

Many of the other symptoms are fatigable, meaning that they get worse as a patient gets tired or develops fatigue. As the day goes on or after activity/exercise, it is common for weakness, balance, numbness, or other symptoms, to get worse.

TREATMENT

Treating MS fatigue is very complicated. Figuring out what to do about it can be overwhelming. Where do you start? There is no single, easy-to-find, and simple-to-do treatment. There are ways to improve MS fatigue but just as the symptom is not straight forward, neither are the solutions. Most MS fatigue is caused by a combination of factors that each contributes a bit to the development of fatigue.

The solution, therefore, is likely to be a combination of little changes that create gradual improvement. There are two types of interventions to manage fatigue. There are medications such as amantadine and modafinil and there are other interventions such as working on sleep, cooling, energy conservation strategies, exercise, and cognitive behavioral therapy that can be more effective. Making changes to manage fatigue is about acknowledging that MS does create some real problems and impose some real restrictions. You can't simply muscle your way through and pretend they don't exist. However, managing fatigue can mean still having a life.

MS fatigue is a real and very complicated problem. It takes time and thought to identify solutions that will work for you.

SPASTICITY

MS-related spasticity occurs when MS activity causes abnormal messages to be sent to muscles, which creates an increase in "tone" or muscle tightness. Spasticity is different from other tightness seen in conditions such as Parkinson's Disease called rigidity. In spasticity, the tightness gets worse the faster you move but in rigidity, this does not matter and the tightness is always there. Everyone needs some muscle tone to maintain an erect posture and conduct daily activities; spasticity occurs when people have abnormally high tone which may interfere with movement.

Generally, the legs are more affected by spasticity than the arms or other muscles, and sometimes patients experience one side of their body being more affected. It can also create difficulties with moving or walking, and can contribute to foot drop, where an individual cannot flex the foot sufficiently to clear the toe while walking. Spasticity contributes to fatigability as the muscle has to work extra hard to overcome this additional tightness so that the muscle wears out faster resulting in fatigable weakness.

Approximately 70% of people with multiple sclerosis (MS) experience difficulty due to spasticity. Signs of spasticity include stiffness, tightness, or involuntary muscle spasms. Spasticity can make mobility difficult, interrupt sleep, as well as be uncomfortable and painful. Severe, untreated spasticity can lead to contractures (restriction of movement in joints), skin breakdown, and pain. Therefore, spasticity should be treated aggressively.

TREATMENT

Fortunately, there are treatments available for the management of spasticity. These can include stretching and exercise routines, physical therapy, and several muscle relaxer drugs are approved for the treatment of spasticity.

To help relieve spasticity, a physical therapist can design an exercise program to increase flexibility, activity level, and overall fitness. A stretching or range of motion program is an important addition to medical management and may help to reduce the requirement for medications.

When spasticity and/or spasms cause discomfort or interfere with daily activities, there are several prescription medications available. For severe spasticity affecting function in a single joint or more focal area, Botox may be considered in addition to muscle relaxers. When medication options are not enough or if there are side effects preventing increasing doses, surgical implantation of a pump to deliver the muscle relaxer, baclofen, directly to the spinal cord may be an option.

SPASMS

Spasms is a term often used for a variety of symptoms. This can include things such as spasticity, tonic spasms, restless leg/limb syndrome (RLS), MS hug, charley horse, Lhermitte's, etc… These can be very painful and tend to be worse when fatigued resulting in problems falling asleep or waking up from sleep. These symptoms are caused by very different things and it is important to work with your provider to identify what type of spasm you are experiencing. It is common to have several of these and for some of them to contribute to other spasms. For example, RLS can often trigger tonic spasms and make these more common and painful.

TREATMENT

After identifying the right type of spasms, treatments can be tried to help relieve them. Some of these spasms are easier to treat with the medications that we have than others. Sometimes treatments can also help figure out what type of spasm it is. This often means having to try different medications to identify the best option and then adjust the dose to find the dose that balances good control of the symptoms while minimizing side effects. Continue to work with your provider to help find this balance.

NEUROPATHIC 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 we experience when we're injured or hurt. You can think of this as the body's alarm system – you spill hot water on your hand, your nervous system sends this alarm from your hand to your brain, you feel pain, and pull your hand away. This is the type of pain that is often treated with opiates.

Neuropathic pain, sometimes labeled chronic pain, is what's often happening with MS patients. This is when your body's alarm system malfunctions. 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, and a pain signal is sent to the brain without an obvious external cause.

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. Neuropathic pain directly related to MS happens when MS attacks nerves in the brain or spinal cord and triggers sensations that are similar to acute pain. It can range widely in severity and sensation and is often felt as a crawling or burning sensation, pins and needles, and throbbing or stabbing sensations in the arms and legs. Shooting pain or an electric shock is another type of neuropathic pain that can be seen in patients with MS. Trigeminal neuralgia and sciatica or a pinched nerve root can also cause this type of pain and these are possible in patients with MS.

Neuropathic pain can also lead to secondary pain – when adapting to or compensating for pain sensations, it is possible to develop wear and tear or musculoskeletal pain resulting in muscle soreness or joint pain. Muscle spasms of the lower back are common from deconditioning and/or weakness of the muscles of the lower back.

TREATMENT

Nociceptive pain that may or may not be directly related to MS can be treated by common means, such as over-the-counter (OTC) medications. While you should always consult your care team before starting a medication, using OTC medications as directed is generally safe. In most cases, these interventions for routine musculoskeletal pain work by treating the cause of the pain – the injury or inflammation that's sending messages to the brain.

Neuropathic pain in MS is much more complicated to treat, mainly because there is no obviously underlying cause. Therefore, it's often treated effectively with prescription medications that are used to treat epilepsy and depression. Both seizure medications and some antidepressants can interrupt abnormal electrical transmissions and block some electrical impulses that are perceived as pain.

There are many possible treatments for secondary pain including physical therapy to strengthen the surrounding area, anti-inflammatory medications, the use of assistive devices or equipment to take the emphasis off the affected area, or even surgery to repair areas of damage. Pain management in these instances may involve a series of trials before it works completely, therefore patience and perseverance is essential and may require consultation with a pain specialist.

NEUROGENIC BLADDER

People living with MS frequently report various bladder issues, and some are surprised to learn that bladder dysfunction can be a neurological problem triggered by MS. Many don't seek help because they don't know they can be helped, and for some, this problem is so embarrassing that they don't want to discuss it — even with their doctor.

Bladder problems and incontinence often result in urinary tract infections (UTI's). Decreased sensation, which is common in MS, can mask the symptoms of a UTI. During a UTI, MS symptoms, including decreased sensation, can become worse. Untreated, these can cause medical complications that pose a risk to a person's general health. MS bladder problems can be caused by a spastic (overactive) bladder, a spastic sphincter (underactive) muscle, or a combination of both (called a dyssynergic or mixed bladder).

A spastic bladder has trouble storing urine. Symptoms of a spastic bladder include:

- **Urgency** (the feeling of having to empty the bladder right now)
- **Frequency** (voiding more often and in smaller amounts)
- **Incontinence** (the inability to hold urine in the bladder)

A tight or spastic sphincter muscle prevents the bladder from emptying. The bladder therefore stores too much urine. Symptoms of a spastic sphincter include:

- **Hesitancy** (the inability to empty the bladder on command)
- **Frequency**
- **Occasional incontinence – due to overfilling of the bladder**
- **Frequent urinary tract infections**

A combination bladder can cause urgency and hesitancy or can mask the need to urinate followed by incontinence.

TREATMENT

The source of the bladder problems should be determined before initiating treatment. A post-void residual can often be done in clinic as a screening test but may require an evaluation by a urologist to identify the exact cause of the bladder trouble. Most bladder issues can be treated successfully, but the exact course of treatment may need to be determined by a medical specialist.

DEPRESSION

Depression is one of the most common and troubling MS symptoms. By some estimates, one in two people with MS will experience depression at some point. This is approximately three times the lifetime incidence in the general population and higher than the rate of depression experienced by people with most other chronic diseases, including other neurological disorders.

The consequences of depression are far reaching and potentially devastating. Depression can interfere with relationships, the ability to earn a living, quality of life, and is associated with a higher overall mortality, including deaths from suicide. Indeed, the risk of suicide in MS is sometimes estimated to be seven times higher than it is among people without MS.

Recognizing depression early can have a great impact on the potential outcomes, and is the first step in getting treatment. It's critical that patients—and their families—stay vigilant for signs of depression, such as fatigue, irritability, tearfulness, loss of enjoyment, sleep disturbance and especially thoughts of self-harm.

But there is good news: depression in MS generally responds well to standard treatments. Based on studies of depression generally, there is strong evidence to support the effectiveness of both medications and some forms of talk therapy, such as cognitive behavioral therapy.

TREATMENT

Most experts believe that the best approach to treating depression is generally a combination of both "talk therapy," such as cognitive behavioral therapy, and medications. Of course, specific decisions regarding whether to use medications should be made based on factors that include the severity of the depression and individual values, such as preferring to avoid medications or lack of resources to support other forms of therapy. Treatment for depression does not always need to be long-term, either – once a relationship with a therapist or mental health professional is established, a proper course of action can be tailored to your needs.

STRESS & ANXIETY

The challenges of living with a chronic condition like MS can be a significant source of stress for individuals. Many people living with MS report believing that stress exacerbates the symptoms of their disease. While stress and anxiety share common features and can often overlap, the key distinction lies in the fact that **stress** is a response to external pressures or demands, whereas **anxiety** is typically a prolonged state of unease or worry often characterized by excessive or irrational fears, even in the absence of an immediate stressor.

Coping with the physical and emotional aspects of the disease, navigating symptoms that may come and go, managing treatments, and navigating the uncertainties of MS can all contribute to heightened stress levels. In addition, it can be stressful to deal with the invisibility of some MS symptoms and to feel that those around you don't understand what you are experiencing. Adjusting and readjusting to changing abilities or needs and financial pressures or concerns about employment can be additional stressors.

Recognizing and effectively managing stress is crucial for individuals with MS. Stress reduction techniques, such as mindfulness, relaxation exercises, and support from healthcare professionals or support groups, can help individuals better cope with both the emotional and physical aspects of MS. By addressing stress, individuals with MS can potentially improve their overall quality of life and well-being while also positively impacting the course of their disease.

TREATMENT

Chronic stress persists over an extended period of time and requires a sustained approach to maintain physical and mental health. Managing it is an ongoing process that takes self-awareness and dedication, and often professional guidance. Rather than dealing with immediate causes and effects, chronic stress management involves making lifestyle adjustments that can lead to better overall stress management and ultimately to an improved quality of life. Here's a concise overview of strategies to manage chronic stress:

- **Stress Reduction Techniques:** Regular practice of stress-reduction techniques like yoga, tai chi, qi gong, meditation, or other forms of exercise can help manage ongoing stress. Look for local community centers offering classes, or head to YouTube or your favorite search engine to look for guided offerings that you can use at home. Many options readily available online feature adaptable exercises like seated yoga that allow you to tailor the experience to your mobility and comfort level.
- **Counseling and Therapy:** Seeking support from a therapist can provide emotional outlets for chronic stressors, and you can work with a therapist to develop coping strategies that fit your situation and lifestyle.
- **Healthy Lifestyle:** There's no shortage of benefits to an overall healthy lifestyle, but one that's not often talked about is its impact on your emotional wellbeing. Things like maintaining a balanced diet, regular exercise, and sufficient sleep can improve your resilience to chronic stress.
- **Social Support:** Building a strong support network of friends and family can not only make you generally happier, but also gives you people who can offer emotional assistance in times of prolonged stress.

HEAT SENSITIVITY

It's estimated that 60% to 80% of people living with MS are sensitive to increased temperatures.

An overheated nervous system does not work as well as one that remains at normal temperature. When a person's body temperature rises, it impairs the ability of the demyelinated nerve to conduct electrical impulses. As temperatures around them rise, people with MS who are sensitive to heat typically describe an increase or re-occurrence of their usual symptoms.

TREATMENT

While we can't control the weather, and there's no direct medical intervention that can help deal with the heat, there are many practical techniques and tools that can help you control the effects of warm weather and other situations that increase core body temperature.

- **Avoid Going Out During the Warmest Time of the Day:** Schedule activities, whenever possible, during cooler times of day: early morning or evening. Early mornings tend to work better for people with MS. The body naturally warms as the day progresses.
- **Wear Light Clothing:** Wear light colors, which will absorb less heat from the sun. Loose fitting lightweight cotton clothing will wick away moisture and improve comfort.
- **Water, Water, Water:** Cool showers or baths can be very helpful when your body temperature is elevated. Fill a spray bottle with water and keep it in the refrigerator for a quick refreshing spray to your face. Swimming is a great low impact, comfortable exercise when you have access to a pool. Keep plastic bottles of water in the freezer and grab one when you're ready to go outside. As the ice melts, you'll have a supply of cold water with you. Be sure you avoid dehydration which will increase your fatigue.
- **Cool Your Environment:** Air conditioning, evaporative coolers (swamp coolers) and fans can cool the air around you or move the air to enhance your own cooling efforts. If you have an air conditioned car, allow it to cool before driving so you don't become symptomatic while driving. If your home has a lower level, organize your home so you spend more time in the cooler areas.
- **Conserve Energy:** During warm weather, pay particularly close attention to pace yourself and lighten your schedule.
- **Exercise Wisely:** Practice moderation and don't overexert yourself. Scale back when needed; some hot days you may need to decrease your exercise time or walk instead of running. Position an electric fan directly towards you when using an exercise machine. Pre-cooling, post-cooling and cooling during the exercise with cooling wraps may help avoid overheating.
- **Cooling Garments:** Wearing cooling garments can have significant impact helping you to get outside and stay active in the summer heat. There are several manufacturers of cooling vests and towels. These systems are great in all climates and can be worn discreetly under clothing if desired.
- **Pre-Plan to Stay Cool:** As with many things in life, it is easier to keep up than catch up! It is easier if you use these strategies BEFORE you are overheated, to avoid becoming overheated. Once you are overheated, you may become symptomatic which will be uncomfortable at best and dangerous at worst. It is best to stay cool so that you limit the effects of the heat.

WALKING & MOBILITY ISSUES

Difficulties with walking are common MS symptoms and can be the result of MS itself (damage to the nervous system in areas impacting motor function) or complications due to other MS symptoms (fatigue, spasticity, or others).

People often report their legs feel weak. Muscle stiffness (spasticity), poor balance, and sensory disturbances such as numbness can contribute to walking problems. Fatigue can increase problems with balance, lower extremity weakness, stiffness, and numbness, which make it harder to walk safely and efficiently.

Toe drag or *foot drop* is a common problem in MS and occurs when one can't lift a foot quite high enough thus catching their toe on the ground, which can result in a fall. People sometimes compensate for foot drop by swinging the hip to the side, bending the knee, or tilting the body to keep the foot from dragging on the ground. These compensations cause an abnormal walking pattern which can lead to lower extremity or low back pain.

TREATMENT

Physical therapists help people determine why they are having trouble walking. A physical therapist will analyze individual gait patterns (how a person walks) and test muscle strength, balance, and sensation to determine specific problems. Based on this evaluation, the physical therapist will recommend a program to address these problems. Recommendations usually fall into five general areas:

- **A comprehensive physical therapy program** can increase muscle strength, endurance, flexibility, balance, and coordination. Programs are tailored to the ability and fitness level of the individual and can be as varied as rigorous fitness programs, hydrotherapy, and wheelchair or seated exercise.
- **Assistive aids,** such as a cane or brace, may be prescribed to improve balance and conserve energy while walking. There are an increasing array of aids available and is a great topic to bring up with your provider as well. Aids can help you do more and shouldn't be seen as a limitation.
- **Energy conservation** techniques can help reduce fatigue and can improve endurance.
- **Practical solutions,** such as a different shoe type, home layout, or walking surface may also be suggested to help improve gait.
- **Medications** are sometimes recommended such as dalfampridine, which can help demyelinating nerves work more efficiently, and muscle relaxers to help decrease spasticity. *(See Spasticity information on page 32).*

COGNITION

Cognition is a general term that refers to the mental activities associated with thinking, learning, and memory. Cognitive dysfunction, also a general term, refers to problems with cognition.

There is both good news and bad news to report about cognitive problems among people with MS. The bad news is that such problems are relatively common, usually estimated to occur in about 45–65% of those with MS. And, not surprisingly, the impact of cognitive problems can be substantial; those with more severe cognitive problems are less likely to work, tend to experience less social involvement, and have more difficulty with everyday tasks. In addition, cognitive problems may make driving dangerous for some.

The good news is that many people with MS will not have any cognitive decline, and many who do see decline will only experience mild problems. In the majority of cases, cognitive decline in MS is not severe. Sometimes, the problems that develop may be focal, affecting only particular aspects of cognition.

Preventing cognitive decline in MS,

obviously, is an important goal. Whether current FDA-approved MS therapies can prevent cognitive dysfunction has received only limited study.

TREATMENT

There is a large and growing body of evidence to support the idea that a lifetime of exercise can result in preservation of a number of aspects of cognition. Much of this literature has focused on aerobic exercise such as walking, running, bicycling and swimming. Even moderate, consistent movement can help with attention, mental health, and fatigue—all of which affect cognition. There are several possible mechanisms by which physical activity could affect cognitive function, including increasing blood flow to the brain, reducing the risk of heart disease and for stroke, and stimulating the growth and survival of brain cells.

In addition to exercise there are a number of other general strategies for reducing age related cognitive decline. These may include maintaining low blood pressure, avoiding obesity, controlling stress and depression, pursuing a life of mental stimulation, and eating a diet rich in antioxidants from fruits and vegetables. Staying cognitively active includes reading, puzzles or brain games, learning something new, engaging in creative hobbies, or even doing work that challenges you mentally. The key is to stay mentally engaged.

Isolation can negatively impact cognition. Having regular social interaction—whether it's meeting a friend for coffee or chatting with a neighbor—keeps your brain working in meaningful ways. Poor sleep can exacerbate cognitive issues. If you're having trouble sleeping, that's worth addressing—sometimes even medically—because the payoff for your brain is significant.

It's also important to manage mental health and stress. Depression and anxiety are common in MS and can cloud thinking. Treating those—whether through therapy, medication, or both—often leads to real improvements in cognitive function. Effective stress management often involves learning and practicing techniques like calming breath work, mindfulness, cognitive reframing, and time management strategies.

Cognitive problems often improve with cognitive or language rehabilitation programs provided by trained speech/language pathologists. These specialists can help patients understand the different types of cognitive problems that are being experienced and help develop strategies to alleviate them. If depression or anxiety are involved, simultaneous treatment with medications or counseling may increase the gains made in cognitive rehabilitation.

Assistive technology can also help address cognitive challenges. For many, a combination of low-tech and high-tech systems can support the cognitive needs in their lives. Often, this ends up being an array of notebooks, alarms, sticky notes, lists, calendars, as well as various functions and apps available on modern smartphones. These tricks and tools are not a crutch—they're smart adaptations.

Talk to your care team. If you notice changes in your thinking or memory, bring them up. There may be interventions, therapies, or even medication adjustments that can help, depending on what's going on.

LIFESTYLE OPTIMIZATION

Living with MS means focusing not only on treatments but also on ways to optimize your overall health and wellness. Taking steps to maintain a healthy lifestyle can play a significant role in supporting your brain health and helping you manage the condition more effectively over the long term. From nutrition and exercise to managing stress, these lifestyle choices can make a difference in how you feel and function.

This section will cover practical strategies to help you take charge of your brain health and overall wellness. By making thoughtful adjustments in areas like diet, physical activity, and mental wellness, you can strengthen your body and mind, giving yourself the best chance to thrive with MS over the long term.

At the Rocky Mountain MS Center, we believe that a multi-pronged treatment strategy to protect the brain and promote brain health offers the best chance to minimize the lifetime impact of MS. This includes several core tenets to promote brain resilience and build brain reserve:

- **The use of disease modifying therapies**
- **Regular physical and mental exercise**
- **Eating well**
- **Social engagement and active participation in life**
- **Stress management**
- **Adequate sleep**

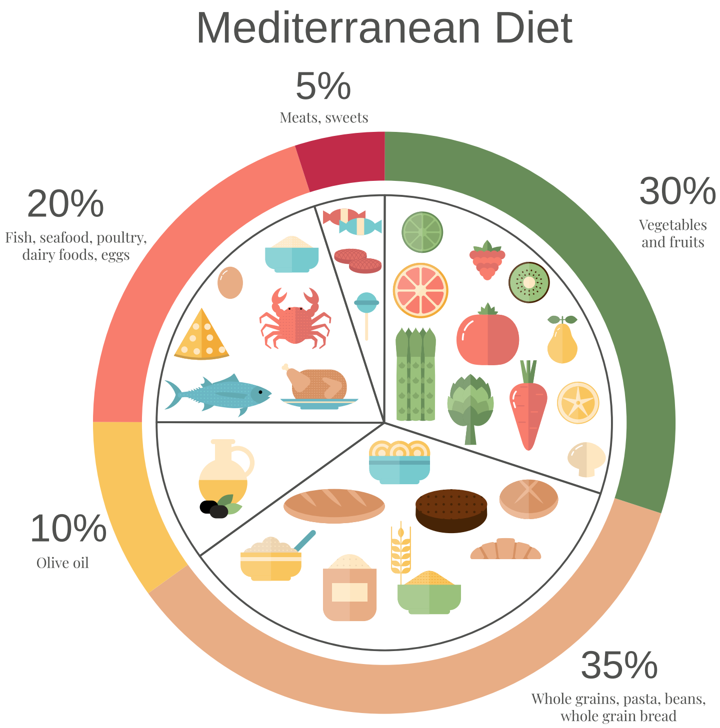
Wellness is defined as the quality or state of being healthy in body and mind, especially as the result of deliberate effort. Wellness strategies are used to prevent the development of secondary medical problems like heart disease, obesity, and diabetes that strain the system and ultimately strain the brain. It's important to remember that physical, emotional, spiritual, and social well-being can be achieved even in the presence of a chronic illness or disability.

We understand that living with a chronic illness like MS can make focusing on these areas of wellness difficult, but it's also why they're so important. Over the next section of this book, we aim to explain the benefits of focusing on each of these areas as well as providing some strategies for small and actionable ways to improve each area. This is not an all-or-nothing effort, and you shouldn't expect to change everything overnight. The bad news is that MS is a chronic illness and isn't going anywhere. The good news is that means that you have time to experiment and see what works for you. Working on better health habits slowly now will pay off exponentially over time.

Nutrition

The most common comorbidities among people living with MS are high blood pressure, high cholesterol, depression, anxiety, and chronic lung disease. Research studies show us that living with MS and these other health problems have been associated with more severe disability and faster disability progression. Risk factors for developing other health conditions are generally the same as for those who don't have MS. They include poor diet (high in calories, sugar, and sodium and low in nutrients), low levels of physical activity, smoking cigarettes, and abusing alcohol and drugs. Possibly the most common and dangerous risk factor is obesity. The CDC also warns that obesity increases risk for heart disease, stroke, type 2 diabetes, and certain types of cancer. Obesity is associated with higher disability and lower physical activity.

The good news is that data from the Institute of Medicine (US) Committee on Quality of Health Care in America suggests



that 80 percent of cardiovascular diseases and 40 percent of cancers are preventable. The committee cites four health protective behaviors as being linked with better health and recovery from illness: Being physically active, eating fruits and vegetables, quitting smoking, and taking medication as prescribed.

There is not one specific diet that controls MS, but eating a diet like the Mediterranean diet that is good for our heart – rich in vegetables, fruits, legumes, and whole grains – is also good for our brains.

The Mediterranean diet has consistently been demonstrated to provide a degree of protection against major chronic degenerative disease. It's associated with reductions in overall mortality, cardiovascular mortality, cancer incidence and mortality. The Mediterranean diet is also associated with improved longevity and is effective against depression and cognitive decline.

TOOLS & RESOURCES

- **Mayo Clinic — Healthy Recipes:** (Mayoclinic.org/healthy-lifestyle/recipes) This is Mayo Clinic's Healthy Recipes website. It gives you a variety of healthy recipes, and you can look up options based on meal, course, number of servings, preparation method, main ingredient, or special diet.
- **Eating Well — Healthy Recipes:** (EatingWell.com/recipes) This site has an extensive number of recipes which are a good blend of tasty but still healthy options. It also has some useful 'how to' videos.
- **My Plate:** (MyPlate.gov) This is the USDA's MyPlate site. It has several great features and toolkits related to healthy eating, diet planning and more. A great tool here is the MyPlate Checklist Calculator, which you can use to calculate your calorie needs and see what foods you should be eating.

Exercise

Physical exercise is important for our general health especially when you are living with a chronic disease like MS. People who exercise regularly have better cardiovascular fitness and are able to manage stress as well as mood and fatigue more successfully. Exercise is good for the heart, and it is also very good for the brain.

Exercise increases the amount of glucose, oxygen, neurotransmitters, hormones and nerve growth factors in the brain which then strengthens the connections between nerves. Exercise is one of the simplest and most direct ways to increase cognitive reserve. Exercise directly influences learning by improving the brain's ability to attend to and process new information. Exercise has been demonstrated to have the best benefit in fatigue related to MS, in part related to helping the nerves function more efficiently. Exercise can also be helpful in regulating regular sleep patterns.

The more you exercise, the more you benefit, even if you have never exercised before. Doing an aerobic exercise program twice a week can improve mood, fitness, and brain health.

According to the Centers for Disease Control, the exercise recommendation for adults is 150 minutes of moderate-intensity aerobic activity every week and muscle-strengthening activities on two or more days. Do what you can do, and occasionally try to do a bit more than you thought you could, but above all, keep moving. It all counts, and it all helps.

PHYSICAL ACTIVITY FOR HEALTH — FINDING WHAT WORKS BEST FOR YOU

You don't have to do all your exercise routine at one time. Doing four 5-minute episodes of exercise can be just as effective as doing one 20-minute exercise routine. Most health benefits come from a moderate exercise program, so intense exercise is not necessary to improve health in general, and brain health in particular.

Getting started with incorporating regular movement into your life can be as simple as taking the stairs instead of the escalator or parking a little further away from the front of the grocery store. If you use an assistive device for walking, or a chair or scooter to get around, there's still plenty you can do to increase your level of activity such as seated tai chi or using a stationary peddler.

Exercise doesn't have to be many hours of strenuous working out five nights a week — it just needs to be an increase over doing nothing. The key is finding what's right for you, what suits your interests, what fits your lifestyle and schedule, and what you can make stick.

DIFFERENT TYPES OF EXERCISE PROGRAMS

There are many possible exercise programs for people with MS. They may include stretching exercises, walking, running, biking, elliptical, swimming, and a range of other exercises that may be appropriate for all levels of physical functioning. Yoga, hydrotherapy (aquatic exercise), and tai chi are great ways to also exercise.

The specific type of exercise program that is best depends on the individual. Each person with MS has specific strengths and weaknesses, and these must be considered when developing an exercise program.

People with MS should also consider developing an exercise program with the guidance of a physical therapist. This is especially important for those with significant physical disabilities or heart or lung conditions. This information should not be used instead of consulting with a professional.

TYPES OF THERAPY

A physical therapist (PT) is a healthcare provider who can help you improve how your body moves. This can include help with symptoms like building muscle strength, adapting to changes in walking, working on balance and coordination, among many other benefits.

On the other hand, an occupational therapist (OT) is a healthcare provider who can help you improve on daily activities, including a focus on hand function.

A speech language pathologist (SLP) is a healthcare provider who can help identify causes for issues with speech and swallowing and create a program to help decrease those symptoms.

TOOLS & RESOURCES

- **Discuss physical therapy options with your neurologist.** This can help you see an expert to start developing an exercise regimen that will work for you.
- **MS Center Hydrotherapy and Online Exercise Programs.** Hydrotherapy is our specialized MS aquatic therapy program designed to improve functional abilities, typically offered two days per week at sites throughout the Denver area. We also provide free

Online Exercise Classes which are seated and adaptive strengthening and stretching workouts conducted via Zoom twice per week. You can find more information on both programs at MSCenter.org/hydro.

Sleep

When we generally think about sleep, we think about its benefit of being less tired. However, numerous scientific studies have found that sleep is critical for many functions: immune system functioning, cognition and memory, ability to multitask, regulating emotions and sensations (such as anxiety, depression, pain) and much more. With either poor quality or quantity of sleep, we can see quite significant implications in patients with multiple sclerosis.

In general, our interactions with the environment cause protein buildup during the day. There is a recycling system, called the glymphatic system, that helps clear out these proteins while we sleep.

Numerous research studies support the theory that sleep is essential to give the body a chance to repair and rejuvenate itself. In fact, it appears that many important processes like muscle growth, tissue repair, protein synthesis, and hormone release occur mostly, and sometimes only, when we sleep.

Sleep is a very complex process. Chronic sleep disturbances, especially in combination with a chronic disease like MS, are usually complicated problems to manage. They seldom have quick and easy solutions. The first step to managing them is to recognize that good sleep is essential to our health.

STRATEGIES FOR GETTING BETTER SLEEP

GOOD SLEEP HYGIENE: Try to go to sleep and wake up at the same time each day. Good sleep begins with having good routine sleep times.

CREATE A COMFORTABLE SLEEP ENVIRONMENT: Make sure that your sleeping environment will promote sleep. Most people can't fall asleep with loud music blaring and bright lights blinking!

- **Temperature —** For most people, cool is better than hot. Try cracking or opening your window. Warm feet are important for falling asleep; otherwise, cooler is better. Temperature regulation seems to be even more troublesome for people living with MS. Consider trying out special sheets or pillows that are meant to help with temperature specifically.
- **Light —** Keep your bedroom as dark as possible. Remember to look for nonobvious sources of light – hide the blinking electric toothbrush; turn the LED alarm clock around so you can't see it. However, if you struggle with proprioception (the ability to tell where your feet are in space – a common symptom associated with some spinal cord lesions), please make sure there is a night light — perhaps motion-activated — on to minimize falls if you get up at night.
- **Noise —** Less noise means more sleep. You can reduce noise levels with rugs and drapes, earplugs, background "white" noise (such as a fan), or soothing music. Music without words may deepen sleep quality greater than music with words.
- **Comfort —** A good mattress and comfortable pillow can improve the quality of sleep.

- **Function —** Try not to use your bedroom for work activities, such as balancing the checkbook, studying, or scrolling through email on your phone or tablet. Make your bedroom a stress-free zone. The bedroom is for sleep and sex only.

AVOID ALCOHOL AND CAFFEINE: Alcohol may help you get to sleep, but it will make your sleep restless and uneasy. Many people who drink experience an alcohol rebound and may wake up early in the morning.

For those who are sensitive to caffeine, it may be best to stop drinking coffee 10 hours before bed.

WATCH YOUR DIET: A heavy meal or spicy foods before bedtime can lead to nighttime discomfort, and fluids can require disruptive trips to the bathroom. A light snack, however, can prevent hunger pangs and help you sleep better.

GET OUT OF BED IF YOU'RE NOT SLEEPING: If you don't fall asleep within 10 to 30 minutes, get up. Get back into bed only when you feel sleepy. The more time we spend in bed lying awake and frustrated, the more our mind associates getting comfortable in bed with anxiety and then we're less likely to fall asleep.

Instead, have a comfortable spot in your home where you can do a soothing activity like reading to calm your overactive mind. Avoid the temptation to turn on the TV or computer, the light stimulation from both just stimulates our brains further though the activities may feel calming.

EXERCISE REGULARLY: Regular exercise has been shown to improve sleep. Exercising in the morning or afternoon – at least three hours before bedtime, so you won't be too "revved up" – will help you get a deeper, more restful sleep. Exercise helps us to burn off those stress hormones that have been triggered in our bodies during the day.

STOP TOBACCO USE: Nicotine, like caffeine, is a stimulant and can cause problems for people trying to fall asleep. Also, as a stimulant, nicotine causes the sleep we do get to be less restorative.

AVOID WATCHING THE CLOCK: Set the alarm and place the clock out of sight. Constant checking can even cause insomnia. Every time we look over and notice more time has passed, we begin fretting about how sleep deprivation is going to interfere the next day.

CREATE A RELAXING BEDTIME ROUTINE: Read a good book, create a soothing bedtime playlist, practice relaxation techniques, or sip on a warm cup of Sleepytime or other caffeine-free tea.

MAKE SURE YOUR URINARY PROBLEMS ARE WELL MANAGED: Many people with MS have urinary frequency. If you are waking up frequently to go to the bathroom and not falling back asleep, it may be helpful to try to address this problem through behavioral strategies (e.g., not drinking within two hours of bedtime, using physical techniques for promoting maximum urination) or medications. Medications can be discussed further with your neurologist.

FOR MORE INTRACTABLE SLEEP PROBLEMS — SLEEP STUDIES AND COGNITIVE BEHAVIORAL THERAPY (CBT): For those who have tried the simple steps above and still have trouble sleeping, it is definitely a good idea to discuss sleep problems with your health care provider. Your health care provider may recommend a sleep study, which may identify specific, medical causes of your sleep issues.

Sleep apnea is increased in MS. Sleep apnea is estimated to affect 3% of Americans, and is estimated to affect between 4-20% of patients with MS. Both obstructive and central sleep apnea are seen at higher rates in MS population. We have a higher suspicion that someone has sleep apnea if they experience: unrefreshing sleep; fatigue that is present from the moment of awakening; morning migraines; nocturnal awakenings for unclear reasons; snoring; or small visible airways.

If medical conditions have been excluded, keep in mind that even severe insomnia can sometimes be managed without medications. Cognitive behavioral therapy for insomnia (CBT-I) includes regular, often weekly, visits to a clinician, who will give you a series of sleep assessments, ask you to complete a sleep diary and work with you in sessions to help you change the way you sleep. Working with a specialist in this way, you should be able to identify and replace thoughts and behaviors that cause or worsen sleep problems with habits that promote sound sleep. There are also web-based resources as well as smartphone apps that can offer CBT-I for those unable to commit to in person therapy visits.

Stress Management

Effectively reducing and managing stress is crucial when living with MS and can play an important role in preventing the development of secondary medical conditions like heart disease, obesity, and diabetes, which can strain the body and, ultimately, impact brain health.

The intersection of stress and MS is a complex and multi-layered relationship. Many individuals living with MS report believing that stress exacerbates the symptoms of their disease. While research hasn't proven this direct connection conclusively, it is very real for those who experience it and certainly strategies to manage and reduce stress are particularly important for those individuals. Although it hasn't been widely studied, some research has shown that individuals living with MS may struggle more than others to identify and understand emotions they are experiencing. This makes it much more important to have tools for recognizing and responding to stress.

And at the same time, the challenges of living with a chronic condition like MS can be a significant source of stress for individuals. Coping with the physical and emotional aspects of the disease, navigating symptoms that may come and go, managing treatments, and navigating the uncertainties of MS can all contribute to heightened stress levels. In addition, it can be stressful to deal with the invisibility of some MS symptoms and to feel that those around you don't understand what you are experiencing. Adjusting and readjusting to changing abilities or needs and financial pressures or concerns about employment can be additional stressors.

With no shortage of stressors to manage, difficulty in recognizing physical signs of stress can also be common when living with MS. Often signs of stress are similar to common MS symptoms like fatigue or muscle tightness. It's important to take notice of emotional and cognitive signs of stress to help you recognize when you need to take action to reduce or manage your stress in different ways. These signs of stress could include excessive nervousness, feeling overwhelmed, being easily distracted, or having difficulty making everyday decisions.

Stress involves the body's complex response to perceived threats or challenges. When we encounter a stressor, such as a demanding situation or a perceived danger, our body initiates a "fight-or-flight" response. The brain initiates a rapid response and releases stress hormones — cortisol and adrenaline.

With the release of these hormones, a range of physical changes occur, including an increase in heart rate, blood pressure, and respiration rate. Emotional responses such as anxiety, fear, frustration, irritability, or sadness can manifest with stress. Stress can also impact cognitive functions like decision-making, memory, and concentration.

It's important to remember that stress isn't always bad – it's a natural response to challenging situations or dangers, and over the course of human history, it's served us well to alert us and protect us. In today's world, it still serves many of the same purposes, but it can also crop up when it's neither wanted nor warranted. Over time, accumulating stressors can sometimes add up to chronic stress. And chronic stress, with the persistent release of stress hormones, can have adverse effects on long-term health, potentially leading to issues such as high blood pressure, suppressed immunity, and increased risk of chronic diseases.

Recognizing and effectively managing stress is crucial for individuals with MS. Stress reduction techniques, such as mindfulness, relaxation exercises, and support from healthcare professionals or support groups, can help individuals better cope with both the emotional and physical aspects of MS. By addressing stress, individuals with MS can potentially improve their overall quality of life and well-being while also positively impacting the course of their disease.

ACUTE STRESS MANAGEMENT: Managing acute stress involves techniques that deal with the immediate emotional and physical reactions to a stressful situation or event. Below are some strategies for managing stressful situations.

- **Mindfulness and Relaxation Techniques —** Deep breathing, meditation, and progressive muscle relaxation — like those in guided "body scan" techniques — can help calm the body's immediate stress response. YouTube is full of guided meditations of all sorts, and apps like Insight Timer and Calm offer free and paid content that's always at your fingertips.
- **Physical Activity —** Engaging in brief physical activity, like a brisk walk or another aerobic activity that gets your heart pumping, can release endorphins and reduce stress. A regular exercise routine is helpful as well, but the immediate impact of simply getting up, moving your body, and increasing your heart rate and blood flow can have significant stress reduction benefits.
- **Acceptance —** It's more challenging than it seems sometimes, but acknowledging and understanding that some things are simply out of your control can go a long way toward reducing their effect on your acute emotional and physical response. Close your eyes, take a few breaths, and accept that you just can't control everything around you all the time.
- **Box Breathing:** A quick and effective stress reducer, box breathing is easy and quick to learn. This technique can be useful in stressful situations when you want to calm yourself or improve concentration.
  - **Step 1:** Breathe in, counting to 4 slowly. Feel the air enter your lungs.

- **Step 2:** Hold your breath for 4 seconds. Try to avoid inhaling or exhaling for 4 seconds.
- **Step 3:** Slowly exhale through your mouth for 4 seconds.
- **Step 4:** Wait 4 seconds.
- **Repeat steps 1 to 4** until you feel re-centered.

Repeat this exercise as many times as you can. Thirty seconds of deep breathing will help you feel more relaxed and in control.

CHRONIC STRESS MANAGEMENT: Chronic stress persists over an extended period and requires a sustained approach to maintain physical and mental health. Managing it is an ongoing process that takes self-awareness and dedication, and often professional guidance. Chronic stress management involves making lifestyle adjustments that can lead to better overall stress management and ultimately to an improved quality of life. Here's a concise overview of strategies to manage chronic stress:

- **Stress Reduction Techniques —** Regular practice of stress-reduction techniques like yoga, tai chi, qi gong, or meditation can help manage ongoing stress. Look for local community centers offering classes, or again head to YouTube or your favorite search engine to look for guided offerings that you can use at home.
- **Counseling and Therapy —** Seeking support from a therapist can provide emotional outlets for chronic stressors, and you can work with a therapist to develop coping strategies that fit your situation and lifestyle.
- **Healthy Lifestyle —** There's no shortage of benefits to an overall healthy lifestyle, but one that's not often talked about is its impact on your emotional wellbeing. Foundational things like maintaining a balanced diet, regular exercise, and sufficient sleep can improve your resilience to chronic stress.
- **Social Support —** Building a strong support network of friends and family can not only make you generally happier, but also gives you a network of people who can offer emotional assistance in times of prolonged stress.

Mental Health & Emotional Wellness

Mental health and emotional wellness are often overlooked when you are taking care of the physical side of a chronic illness like MS. It can be extremely difficult to prioritize one's emotional health when there are so many other pressing needs, but if you are experiencing an unhealthy level of negative emotions, it can have a major effect on other areas of your health such as sleep, energy level, relationships, nutrition, and more.

Being diagnosed with a chronic illness like MS means that you must process and adapt to changes that you haven't planned for. There is usually a period of shock, maybe some denial, grieving the life you thought you would have, and hopefully acceptance and adjustment. These phases do not necessarily occur as a linear process, and you may have to revisit them as your MS changes over time.

You do not need to be in the "acceptance" stage to improve your emotional wellness. You can work to increase and build up your emotional wellness at any time. Although there are many areas to explore within emotional wellness, let’s discuss a few that come up often.

MS AND ANXIETY & DEPRESSION

Anxiety and depression are common symptoms of MS. Though the numbers vary from different sources, it seems likely that upwards of 60% of people living with MS experience symptoms of depression and/or anxiety, a much higher percentage than the general population. These feelings can be the result of a new diagnosis, a change in function and ability due to MS, or can be caused by the neuro-inflammatory or neuro-degenerative process of the disease itself.

Depression and anxiety are treatable, even when another condition like MS is present. Even mild depression can affect your overall well-being and should be taken seriously. If you think you may be experiencing feelings of depression or anxiety, it is important to speak to a healthcare professional to see what options are available to you. You can start with your PCP, neurologist, or a mental health professional like a licensed clinical social worker (LCSW) or therapist.

For many people living with MS, a combination of talk therapy and medication can be very helpful. You may only need this extra support for a short amount of time, but it can be vital to getting you through a rough spot. *Please see Depression and Anxiety sections on pages 36-37 for more specific information and guidance.*

MAKE EMOTIONAL HEALTH A PRIORITY

Schedule emotional health time so it’s got a space on your calendar. It is often easier to proactively maintain emotional well-being by regularly spending time focused on it, rather than playing catch-up once you’re drained. Spending time outdoors, mindful stretching, seeing a friend for coffee, journaling, or petting an animal can boost your mood and energy and allow you to become more resilient.

988 Lifeline

988
SUICIDE
& CRISIS
LIFELINE

No matter what problems you’re dealing with, whether or not you’re thinking about suicide, if you need someone to lean on for emotional support, **call the 988 Lifeline.**

How you handle stress directly feeds into your emotional well-being. **Please see page 47-49 for some helpful stress management strategies.**

Making emotional well-being a priority also means regularly checking in with yourself and honestly evaluating how you are feeling. This check-in should encompass your emotional, mental, and physical state. Emotions can manifest physically and paying attention to things like a racing heart, headache, or upset stomach can give you clues that something is wrong and a place to start to fix it. Taking a few deep breaths can slow a racing heart while also grounding you and giving you the opportunity to delve deeper into the feeling.

If you’re feeling overwhelmed, is there something that you can reach out for help with? There are many different types of people you can ask including support partners, friends, family, and health professionals like your doctor or a therapist. Most of the people in your life would love the opportunity to show how much they care but they aren’t sure of the best way. Have a conversation about what would truly be helpful to you to involve them.

Emotional wellness is not a destination, and the path is not linear. You may feel great one day and distressed the next, you may find an extremely helpful strategy that doesn't work 100% of the time. It's okay, normal, and expected to use different strategies in different situations and on different days, and some days you may need to sit with uncomfortable emotions because that's part of being human too.

Complementary and Alternative Medicine

Many people living with MS may choose to supplement their medical treatment with **complementary and alternative medicine (CAM)**, which refers to unconventional medical practices that are not part of traditional medicine.

One of the biggest things to keep in mind is that complementary medicine is intended to be exactly as its name states: complementary. One of the core tenets that we have learned about MS through the years is the importance and high effectiveness of our disease modifying therapies.

One the challenges with CAM is a lack of clear robust scientific data that supports its practice. Although the information available to the general public is vast, it is often of very questionable quality. Established medical and research practices are highly regulated and come with built-in transparency, painstaking data-gathering, and exhaustive evaluation and trial processes. No such processes exist for most things that fall into the CAM category, so the average person is left searching through a lot of information that may not be as reliable as they think.

This makes it absolutely critical to speak to your medical team before undertaking any complementary or alternative treatment. While it's true that many things falling into the CAM category can be innocuous or harmless, some may not be as mundane as they seem. You should seek the advice of a medical professional who knows you and is familiar with your medical treatment plan before moving forward with any additional treatments or practices.

Although it's impossible to provide a complete list of CAM treatments that could potentially be useful for MS, representative examples of therapies are:

- **Biologically based therapies:** diets, herbs, vitamins, other supplements
- **Alternative medical systems:** acupuncture, Ayurveda, homeopathy
- **Mind-body medicine:** relaxation methods, biofeedback, tai chi, yoga
- **Manipulative and body-based systems:** chiropractic, massage, reflexology
- **Biofield medicine:** therapeutic touch
- **Bioelectromagnetics:** magnets, pulsing electromagnetic fields

Notes

YOUR MS CENTER TEAM & RESOURCES

“Rocky Mountain MS Center” jointly describes two elements of an innovative partnership — the **RMMSC at CU clinical and research teams** operating at UCHealth and the University of Colorado Anschutz Medical Campus, and the **RMMSC nonprofit organization** that provides support, education, fundraising, and community programs.

In this section, we’ll introduce you to the many people who make up our team and describe some of the core elements of what we offer our MS community.

Clinical Care Team

The Rocky Mountain MS Center at University of Colorado consists of a large and dynamic team of professionals who directly serve patients, conduct and manage our research efforts, and handle all the logistics of one of the most comprehensive patient-focused MS centers in the world

The clinic team can be quite extensive! As way of a quick introduction, here is a list of some of the people who will help provide the best care possible. This is constantly evolving and is not meant to be fully comprehensive.

- **Doctors —** Can be Medical Doctors (MDs) or Doctors of Osteopathy (DOs). They work with the other team members to help provide the best care for our patients.
- **Advance Practice Providers (APPs) —** a combined term for Nurse Practitioners (NPs) and Physician Assistants (PAs). They can see patients on their own but work closely with doctors to see patients. They help improve access to the clinic and can provide a different perspective to help improve patient care.
- **Schedulers —** This group of team members will help with getting patients into the right clinic and type of appointment such as a new or return appointment with the right provider team.
- **Front desk staff —** They will greet you and get you checked in when you arrive at the front desk. They check to make sure that the visit is authorized by insurance and may help you check-out if needed.
- **Medical Assistants (MAs) —** They bring patients to the exam room, ask some questions required by governing bodies, and take your vitals. They will also draw blood if needed, help you check-out, and schedule a follow up appointment.
- **Nurses —** Are usually the first line of contact for messages into the clinic but also help coordinate care for patients such as infusions. When you send messages to your physician through the My Health Connection portal, it will go to our specialized MS nurses first. If they are unable to answer your question, they will either direct your message to your neurologist or ask for you to schedule an appointment for more complex questions.
- **Pharmacists —** They work in the team to get medications to patients. They check that drugs do not interact and come from the right pharmacy. In our clinic, we have a specific pharmacist who can help with counseling for new medications and help troubleshoot with some side effects.
- **Social Workers —** Provide resources and try to assist patients who need help in coordinating their care. Our MS social worker can be of great help with housing resources, insurance aids, travel resources, etc.
- **Neuropsychologists —** Can help coordinate and/or provide mental health resources to patients. Our neuropsychologist can meet with patients to help them with skill development, such as dealing with stress, adjusting to a new diagnosis, management strategies for depression and anxiety and more.

Meet Our Team

Scan the QR code here to meet some key members of our team at the RMMSC at University of Colorado.

Are You a Candidate for MS Research Studies?

The Rocky Mountain MS Center at University of Colorado needs YOU!

You can find a complete list of the MS Center's current research studies and trials at **MSCenter.org/research**. If you are interested in research, even if you don't qualify for any current studies, contact the Research Recruitment Department to get added to the interest list and they will reach out to you with future studies.

University of Colorado
Anschutz Medical Campus

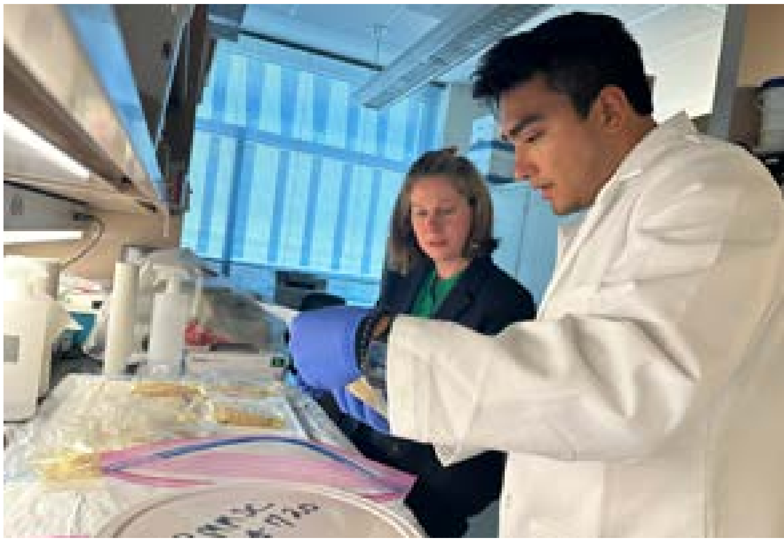
CALL: **(303) 724-4644** or EMAIL: **neuroresearch@cuanschutz.edu**

Research

At the Rocky Mountain MS Center, we know that clinical research is critical to understanding this disease's complex triggers and effects and will lead to better treatments and ultimately the cure.

The Rocky Mountain MS Center at University of Colorado is the home of one of the largest MS research programs in the world. The success of our clinical research programs depends on the broad support of the MS community in the Rocky Mountain MS Center region. Two key elements of our extensive research efforts are:

- **Clinical Research —** Our active MS clinical research program gives opportunities for patient participation in emerging therapies and treatments. Call 303-724-4644 for more information or visit MSCenter.org/research.
- **RMMSC Tissue Bank —** Playing a vital role in finding a cause and cure for MS, the Tissue Bank acquires, processes, preserves and distributes post-mortem brain and spinal cord tissue for research. Call 303-788-4030 ext. 149 for more information. *If your call is concerning an urgent tissue bank donation, including the death of a donor, please call 720-626-6060.*



Research

Scan the QR Code or visit **MSCenter.org/research** to learn more about our research program, including links to the Research program at the RMMSC at CU and information on participating in research efforts.

Education

Education programs are the backbone of the Rocky Mountain MS Center's services for the general public — both for MS patients, and for their families, friends, neighbors and colleagues.

MS 101 is a free 2-hour class on Zoom for anyone newly-diagnosed and their support partners in a small-group setting that allows for a discussion tailored specifically to you.. The presenters go over the basics of MS, how our understanding of the disease has changed over the years, and what we know today. To register for an upcoming session, visit us at **MSCenter.org/ms101**.

Conversations on MS brings our neurologists around Colorado and into your home via Livestream, for informative question and answer events, educating about MS and informing patients about research developments. For a schedule of upcoming sessions, visit **MSCenter.org/conversations**.

Twice a year, our **Education Summits** feature presentations and discussions with leading minds in the care and treatment of MS. We present these half-day events in the spring and fall, free of charge to all attendees. Join us live in the Denver area, or watch the livestream from home. For information, upcoming schedules, and our complete archive of part Summits, please visit **MSCenter.org/edsummit**.

We're pleased to bring you a series of **Webinars** on a wide range of topics that you've told us you would like to learn more about. View upcoming webinars or browse our complete archives at **MSCenter.org/webinars**.

We strive to provide materials and resources to help patients and support partners make informed decisions about their care, and for the rest of our community to better understand what it's like to live with multiple sclerosis. Learn more about these and other our education opportunities at **MSCenter.org/education**.

Support Services

In our efforts to promote quality of life for patients and their families, we are committed to providing services that support individuals and families with MS throughout their entire MS journey.

We understand that every person experiences MS differently, and that one person's MS can have a profound impact on their loved ones as well. Led by MS

Education Programs

Scan the QR code to learn more about the many FREE education opportunities from the MS Center.

Support Services

Scan the QR Code or visit **MSCenter.org/support** for more about our support programs.

counseling and education experts, we offer counseling and support services to clients and their families, and referrals to experienced and qualified professionals for further treatment.

Through the MS Center's **Counseling Services**, we offer a range of resources to assist each individual, as well as families and friends. Mental health issues are varied and wide-ranging, but can include depression, anger issues, stress, and anxiety. Learn more and get in touch with an MS-specialized counselor at **MSCenter.org/counseling**.

Individuals between the ages of 21-45 are invited to join our **MS Young Professionals Network (MSYPN)**. Younger adults experience some of the highest rates of diagnosis of MS — and it can be a very isolating experience, especially for a young person in the prime of life. MSYPN provides regular opportunities for younger adult peers to share their experiences with, learn from, and support one another. Learn more at **MSCenter.org/msypn**.

Learn more about our various other support services — including legal services, disability assessment, MS ID Cards, and more — at **MSCenter.org/support**.

Direct Care

The Rocky Mountain MS Center is driven by a comprehensive care approach that maximizes and enhances the brain's ability to protect and repair itself and to promote quality of life for patients and their families. This means treating early and treating aggressively.

Leading our direct patient care efforts is the

Rocky Mountain MS Center at University of Colorado — home to our neurologists, advanced practice providers, nurses, and extensive support staff of highly-trained, MS-specialized professionals. We're proud to have assembled one of the leading teams of MS specialists in the world right here at the RMMSC @ CU.

Our team works primarily out of the Outpatient Pavilion on the University of Colorado's Anschutz Medical Campus. However, we also serve patients at other local facilities, including Children's Hospital Colorado, the Denver VA Medical Center, and Denver Health. Learn more and contact our medical team at **MSCenter.org/clinic**.

Complementing the Clinical Care team at the RMMSC at CU is the **King Adult Day Enrichment Program (KADEP)**, an innovative, community-based and cost-effective day program alternative to nursing home placement for younger adults with MS, brain injury, stroke and other neurological conditions. KADEP provides a dynamic array of classes and activities, nursing care and other services designed to enhance the physical, emotional, cognitive and social wellbeing of each participant, supervised by an on-site licensed nurse and support staff. Learn more at **MSCenter.org/KADEP**.

Engagement & Awareness

Living with MS can be challenging for so many reasons, but one of the most common is having your condition misunderstood by those around you. The MS Center's awareness efforts aim to create more understanding about MS, and give you the tools to help others in your life understand the disease.

Every March, **MS Awareness Month** gives us 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. We hope you'll join us as we dedicate the month to educating our friends, helping foster greater connections, and giving back to our MS Community. While we celebrate in March, you can learn more about Awareness Month all year long at **MSCenter.org/awareness**.

SEE-MS *(Sparking Education and Empowerment in MS)* aims to build more awareness of MS at the community level. We are committed to fostering health equity by working to help ensure everyone has access to comprehensive specialty care and educational resources that have the power to change lives.

We want every person living with MS to feel fully heard and supported by their community and care team, regardless of where they live. Learn more and get involved at **MSCenter.org/seems**.

Finally, our **Rural Engagement Program** aims to build strong connections and lasting relationships with people and families living with MS in rural communities throughout Colorado. This program features regular community forums and educational opportunities in towns throughout our region, bringing the expertise of our MS specialist neurologists, educators, and support service providers to those who may not be able to easily join us in the Denver area. Learn more at **MSCenter.org/rural**.

Advocacy

The Rocky Mountain MS Center is a proud member of the Chronic Care Collaborative (CCC) — a group of more than 50 different health organizations in Colorado representing a wide range of chronic diseases. The Collaborative meets at least monthly to discuss policies important to member organizations and their constituents. The CCC advocates at the Capitol to the State General Assembly every year on Chronic Disease Awareness Day where they educate legislators about the burdens of chronic disease on families, budgets, and people's lives.

Advocacy is not limited to organized events like Chronic Disease Awareness Day. While we always remain nonpartisan, there are times

Advocacy

Make your voice heard! Join us as a patient advocate, share your story, and stay informed about issues that impact people living with MS.

when legislators need to hear from people like you. It's your right to talk to your legislators, and share with them the unique perspective of someone whose life has been touched by multiple sclerosis.

We encourage you to contact your state and national legislators and share your personal story with them. Learn more about our advocacy efforts and get involved at **MSCenter.org/advocacy**.

Volunteers

Volunteers at the MS Center find their place — something that interests them and matches with their time and talents. Join with other volunteers to provide valuable services including:

- **Volunteering at the King Adult Day Enrichment Program (KADEP):** Volunteers are needed at our specialized adult day program, which operates weekdays. Volunteers may assist a client with a craft project, help serve lunch, help a client in a wheelchair on a field trip into the community, work in our many gardens, or even teach a class on a topic of your personal interest and skill.
- **Hydrotherapy Volunteers:** Volunteers assist at our hydrotherapy (water exercise) programs held weekdays around the Metro area. Volunteers may assist clients in the dressing room, help with the hydrolic lifts to get clients in and out of the pool, assist in the water, or serve refreshments following the exercise program.
- **Special Events Volunteers:** You can volunteer to plan and implement one of our special events, such as our Annual Gala, Education Summits, MS Awareness Month in March, MS4MS over the summer, and more!
- **Office Assistance:** Help out in our administrative office, assisting with mailings, event preparation, marketing efforts and general office needs.

To learn more about volunteer opportunities with the MS Center, please call 303-788-4030 x. 111, email volunteer@mscenter.org or fill out our Volunteer Application at **MSCenter.org/volunteer**.

Volunteering

Scan the QR code to learn about volunteer opportunities at the MS Center, and to sign up as a Volunteer with us.

Notes

MORE RESOURCES

Managing MS often takes a team, and while the Rocky Mountain MS Center is here to support you, there are many other resources available to help you navigate life with MS. From national organizations to legal assistance to health and exercise supports, these resources can provide additional information, connection, and practical tools to help you along the way.

In this section, you'll find a list of trusted organizations, websites, and services that offer everything from educational materials to financial assistance and advocacy. Whether you're looking for specialized medical guidance, emotional support, or help with daily challenges, these resources can be valuable additions to your MS journey.

MS Organizations & Support Services

Rocky Mountain MS Center (RMMSC): The RMMSC is a non-profit focused on providing care, support, education, and research for patients and families living with MS. We offer a wide variety of programs and services designed to meet you wherever you are in your experience with MS, including in-person and online learning opportunities as well as a robust library of past programs on our website and YouTube channel. We've provided this New Patient Guide to get you started, and invite you to join any of our education programs, explore our many additional resources on our website, connect with us on social media, and contact us directly if there's anything else we can do for you.

- **Website: MSCenter.org**
- **Contact: 303-788-4030**

Multiple Sclerosis Association of America (MSAA): MSAA provides free programs and services to individuals with MS, including a toll-free Helpline, cooling equipment, medical equipment assistance, and educational resources. Their MRI Access Program helps eligible individuals with the cost of diagnostic imaging.

- **Website: mymsaa.org**
- **Helpline: 800-532-7667**

Multiple Sclerosis Foundation (MS Focus): MS Focus is committed to improving the lives of people with MS through financial assistance programs, support groups, educational materials, and grants for medical equipment and emergency needs. They also provide wellness programs and caregiver support.

- **Website: msfocus.org**
- **Contact: 888-MSFOCUS (673-6287)**

National Multiple Sclerosis Society (NMSS): The National MS Society is a nonprofit organization dedicated to funding research, advocating for policy changes, and providing resources for people living with MS. Their MS Navigator Program offers personalized support to help individuals find doctors, financial assistance, and local programs.

- **Website: nationalmssociety.org**
- **Contact: 800-344-4867**

Can Do MS: Can Do MS offers educational programs, coaching, and wellness resources to help people with MS and their families live healthier, more active lives. Their programs focus on nutrition, exercise, mental well-being, and overall lifestyle management

- **Website: cando-ms.org**
- **Contact: 800-367-3101**

Medical & Research Resources

Consortium of Multiple Sclerosis Centers (CMSC): The CMSC is a network of MS healthcare professionals, clinics, and researchers dedicated to improving care for people with MS. They provide educational materials, a directory of MS specialists, and research updates.

- **Website: mscare.org**
- **Contact: 201-487-1050**

MS International Federation (MSIF): MSIF is a global network of MS organizations that supports international MS research, advocacy, and education. They provide resources for people newly diagnosed, updates on global MS research, and connections to MS organizations worldwide.

- **Website: msif.org**

National Institute of Neurological Disorders and Stroke (NINDS): NINDS is a division of the National Institutes of Health (NIH) that conducts and funds research on neurological disorders, including MS. Their website offers detailed information about MS research, clinical trials, and treatment advancements.

- **Website: ninds.nih.gov**
- **Contact: 800-352-9424**

Financial & Medication Assistance

HealthWell Foundation: The HealthWell Foundation provides financial assistance for underinsured patients who need help covering the cost of medications, co-pays, and insurance premiums, including MS treatments.

- **Website: healthwellfoundation.org**
- **Contact: 800-675-8416**

Patient Access Network (PAN) Foundation: The PAN Foundation offers financial assistance grants to help cover out-of-pocket costs for MS medications and treatments for eligible individuals.

- **Website: panfoundation.org**
- **Contact: 866-316-7263**

Wellness & Mental Health Support

Breckenridge Outdoor Education Center (BOEC): BOEC is a nonprofit organization offering life-changing outdoor experiences for individuals of all abilities, including people living with multiple sclerosis. Set in the Colorado Rockies, BOEC provides adaptive skiing, wilderness retreats, high-ropes courses, and more—designed with safety, accessibility, and empowerment at the forefront. For those with MS, these programs offer a unique opportunity to build confidence, connect with others, and enjoy the restorative benefits of nature in a supportive and inclusive environment.

- **Website: boec.org**
- **Contact: 800-383-2632 (BOEC), or 970-453-6422**

First Descents: First Descents is a Denver-based nonprofit that offers free, fully adaptive outdoor adventures—including kayaking, rock climbing, surfing, skiing, and more—specifically designed for young adults living with multiple sclerosis. These week-long core programs and shorter community adventures are focused on empowerment, accessibility, and healing through nature. First Descents delivers an opportunity to rediscover strength, community, and joy in the outdoors—all at no cost to eligible participants.

- **Website: firstdescents.org**
- **Contact: 303-945-2490**

National Alliance on Mental Illness (NAMI): NAMI provides mental health resources, crisis support, and education for people living with mental health conditions, including depression and anxiety, which are common in MS. They also offer support groups and a free helpline.

- **Website: nami.org**
- **NAMI Helpline: 800-950-NAMI (6264)**

MS Friends Peer Support Program (Offered by the National MS Society): This peer support program connects people with MS to trained volunteers who can provide emotional support, shared experiences, and encouragement via phone.

- **Website: nationalmssociety.org/Resources-Support**
- **Contact: 800-344-4867**

Employment & Disability Resources

Job Accommodation Network (JAN): JAN provides free, expert guidance on workplace accommodations and disability employment rights under the Americans with Disabilities Act (ADA), helping people with MS navigate workplace challenges.

- **Website: askjan.org**
- **Contact: 800-526-7234**

Stewart Disability Law Firm: Tom Stewart is an attorney and physician assistant who has worked with the Rocky Mountain MS Center and its patients for more than two decades. Stewart specializes in helping individuals with chronic disease receive Social Security Disability benefits. His depth of practice in Social Security Disability law includes high success rates at the initial and hearing levels. As a medical professional, he is well equipped to work in concert with your care providers to develop the required evidence of disability.

- **Website: stewartdisabilitylaw.com**
- **Contact: 720-301-9708**

Social Security Disability Insurance (SSDI) & Supplemental Security Income (SSI): People with MS who can no longer work may qualify for SSDI or SSI benefits through the Social Security Administration. The SSA website provides details on eligibility, application processes, and disability determination criteria.

- **Website: ssa.gov/disability**
- **Contact: 800-772-1213**

Advocacy

Colorado Consumer Health Initiative (CCHI): CCHI's Consumer Assistance Program helps Coloradans who experience issues with their health coverage. They can help you navigate hospital financial assistance programs, surprise medical bills, health care denials, claims issues, and negotiating payment plans with doctors, clinics, hospitals and collections agencies. CCHI can also refer you to health coverage enrollment assistance and to other basic needs programs like food and energy assistance. Please complete this inquiry form and they will contact you.

- **Website: cohealthinitiative.org**
- **Contact: 303-839-1261**

Chronic Care Collaborative (CCC): The CCC is made up of over 50 different voluntary health organizations representing a wide range of chronic diseases. The CCC is dedicated to improving access to quality, affordable, and integrated healthcare.

- **Website: chroniccarecollaborative.org**
- **Contact: 303-993-5056**

THANK YOU

for making a difference.

When you support the RMMSC's nonprofit 501(c)(3), you're helping the Rocky Mountain MS Center expand programs, services and research efforts in our community. We provide a wide range of patient and community education programs, we work together to provide our community with a truly comprehensive approach for people and families living with MS and related neurological conditions.

COMMUNITY EVENTS

Find out what's coming up! The MS Center hosts regular community and fundraising events, including our annual Gala and our Multiple Summits 4 MS Flat 14er.

MONTHLY GIVING

Show your support and commitment to our cause by becoming a Friend of the Rocky Mountain MS Center! Monthly donations of any amount are a sustainable way to support us.

MAKE A DONATION

Support from people like you is critical to our ability to provide programs and services to our MS community. Make a quick and easy donation, or learn about more ways to make an impact.

PLANNED GIVING

Planned giving ensures the long-term sustainability of the RMMSC through generous legacy gifts. This investment shows selfless devotion and commitment to the future of our organization.

MSCENTER.ORG

Connect with us! Search for
"Rocky Mountain MS Center"
on social media.

University of Colorado
Anschutz Medical Campus

ROCKY MOUNTAIN
MS CENTER
— the answers begin here —

uchealth

Rocky Mountain MS Center
Nonprofit Administration
Education Programs & Support Services
8845 Wagner Street
Westminster, CO 80031
Nonprofit: (303) 788-4030

Rocky Mountain MS Center
at University of Colorado
Clinical Care Team
1635 Aurora Court, 5th Floor
Aurora, CO 80045
Clinic: (720) 848-2080

MSCENTER.ORG

info@mscenter.org

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