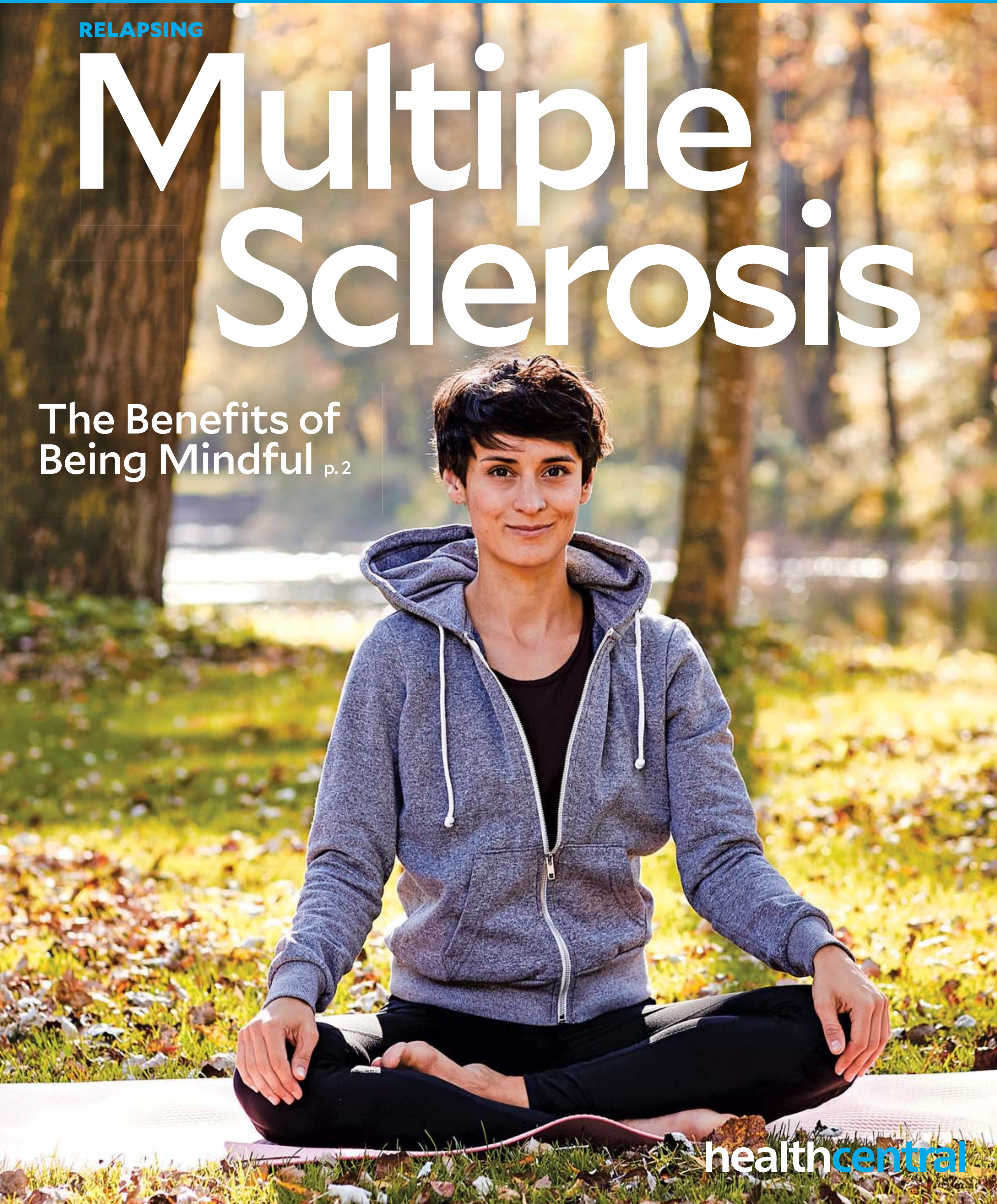
Making Music With MS p. 12

What's Your Risk of Getting COVID-19? + Best of the MS Blogs + Treatment Roundup

RELAPSING

Multiple Sclerosis



The Benefits of Being Mindful p. 2

healthcentral

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

Find Your Calm

MINDFULNESS—the practice of tuning out external thoughts and focusing on breathing and bodily sensations in the moment—might help with the negative emotions and cognitive changes often associated with MS.

In a study published in *Rehabilitation Psychology* in May 2020, 61 people with MS were assigned to one of three groups: mindfulness training; adaptive cognitive training, in which computer games are used to improve cognitive abilities; or a control group with no training. After four weeks, people in the mindfulness group were better able to regulate negative emotions than those in the other groups.

Another study published in the July 2020 issue of *Neuropsychology* found that practicing mindfulness regularly boosted participants' processing speed—the time it takes to receive, understand, and respond to new information—which often declines in people with MS.

Short videos about the technique can be found at **mstrust.org.uk/a-z/mindfulness**.

2.5 **Millions of people in the world who have MS**

EXERCISE FOR EVERY STAGE OF MS

Research clearly shows that working out—as well as everyday activity—has abundant benefits if you're living with MS. Yet people with MS tend to be less active than those who don't have the condition. Hoping to rectify the situation, the National Multiple Sclerosis Society has now developed guidelines and instructional videos to encourage exercise at every stage of MS.

The guidelines suggest that people with MS get at least 150 minutes per week of exercise (30 minutes, five times a week) and another 150 minutes of movement from activities like housework and job duties.

The free video series includes demonstrations of stretching, breathing exercises, and aerobics that can be done at home. For links to the videos, go to **nationalmssociety.org** and search for "exercise and physical activity recommendations." (Get an OK from your doctor before starting any exercise program.)

More Reasons for Regular Checkups

People with MS commonly experience additional medical conditions. And data published in the journal *Neurology* in August 2020 suggests that having other disorders can affect MS progression and relapse rates.

Researchers studied the medical records of more than 900 people with MS enrolled in a drug trial and followed them for several years. Those with anxiety or elevated cholesterol were more likely to experience relapses and a worsening of their condition. Having two or more disorders of any kind in addition to MS was linked to a greater relapse risk, compared with having just one.

The findings raise the possibility that treating seemingly unrelated health problems could have a positive effect on MS activity, says study coauthor Amber Salter, PhD, MPH, assistant professor of biostatistics at Washington University in St. Louis, Missouri. Either way, getting treatment for other conditions is bound to improve your quality of life.

FROM LEFT: ISTOCK; GETTY IMAGES; ISTOCK. COVER: GETTY IMAGES

Q&A

Does my MS disease-modifying therapy (DMT) increase my risk of getting COVID-19 or having complications from it?

MS itself doesn't increase the risk of getting COVID-19 or the severity if you do get it—unless it's more advanced MS. The main risk for severe infection relates to your age; comorbidities such as heart disease, hypertension, or diabetes; and morbid obesity. When it comes to DMTs—we now have 20 different ones—we still don't have definitive data on how they affect the risk of getting COVID-19. Older injectable drugs, such as interferons, are completely safe. In fact, interferons may potentially lessen the severity of COVID-19. Oral agents do not appear to bring an increased risk for severe infection either. The big concern is with drugs that get rid of B cells [white blood cells]—patients on these may have a slightly higher risk for severe COVID-19 infection.

■ If some medications do indeed increase the risk of getting the virus, what can be done?

We do not recommend changing drugs because of the COVID situation if you're doing well with a particular drug. But if you're concerned, talk with your MS healthcare provider. It is important to be particularly diligent about following the guidelines for personal protection—that means wearing a mask, practicing social distancing, washing your hands before and after you go anywhere, and avoiding circumstances where you may be exposed to the virus.

FROM TOP: ISTOCK; AARON MILLER, MD

■ How could the level of my MS progression affect the severity of COVID-19 if I get it?

People who have greater disability from multiple sclerosis are at increased risk for a more severe COVID infection. Part of the reason has to do with age. [People with more advanced MS are also typically older, which is a risk factor for COVID-19 severity.] But greater neurological disability can also increase severity risks by potentially reducing your lung capacity and making it harder to clear secretions.

■ My anxiety level has increased during the pandemic and I'm not sleeping well, which is worsening my daytime fatigue and ability to function with MS. What can I do?

It's certainly understandable that people are experiencing increased anxiety during this time. But if your anxiety level is interfering with your ability to sleep, I suggest getting some professional help through psychotherapeutic approaches—even through telemedicine—or medications [as prescribed by your doctor].

■ I'm due for an MRI. Should I postpone in-person medical appointments?

MRI is a critical part of care for people with MS. But if nothing is going on for you clinically, you may want to postpone it for a month or two. This is an issue of weighing risks and benefits on an individual basis, depending on the level of COVID activity in your community. It needs to be discussed with your MS doctor.

■ When a vaccine for the novel coronavirus becomes available, will my MS or meds I take affect my ability to get vaccinated safely?

This is a question that we in the field of MS are going to be grappling with, hopefully sooner than later. The answer will likely vary with the DMT that someone is taking. ■

AARON MILLER, MD, is a professor of neurology at the Icahn School of Medicine, and medical director of the Corinne Goldsmith Dickinson Center for Multiple Sclerosis at Mount Sinai Hospital in New York City.

Managing MS means you can keep enjoying the things you like to do with your loved ones.

MS Explained

The good news: A better understanding of multiple sclerosis progression and newer, more effective treatments have made this challenging disease easier to live with for many people.

2.5%

Increase in risk of developing MS if there's a family history of the condition

If you're sitting in an MS infusion center as you read this, you already know that multiple sclerosis is a chronic, progressive disease of the central nervous system in which the immune system mistakenly attacks myelin, a fatty substance that insulates your nerves and helps them communicate. Over time, these attacks can cause scarring (known as sclerosis or lesions) and hardening of nerve tissue in the spinal cord, brain, and eyes. The lesions can cause pain and weakness in the extremities, vision issues, and cognitive problems. Because the exact locations of MS damage vary from person to person, so do the severity, symptoms, and course of the disease.

GETTY IMAGES

913,900

Estimated number of MS cases in the United States

Who's at Risk

For first-timers at the infusion center, you may still be wondering how and why you ended up with MS. Here are some possible risk factors:

- Female gender; estimates vary, but about three times as many women as men have MS.
- Where you live or grew up; MS is more prevalent farther from the equator.
- Northern European ethnicity
- Family history of the disease
- Certain genes
- Exposure to certain infections, like Epstein-Barr, human herpes virus 6, and *Chlamydia pneumoniae*
- Low levels of vitamin D
- Smoking
- Obesity (a recently identified risk)

Diagnosing RRMS

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

CIS is characterized by an episode of neurological symptoms that lasts at least 24 hours, caused by inflammation of or damage to myelin in the central nervous system. Some people who experience CIS go on to develop MS of one form or another, and some don't.

About 85 percent of people with MS are initially diagnosed with RRMS. Several factors distinguish RRMS from other forms of MS, according to the National Multiple Sclerosis Society.

- Diagnosis at an earlier age
- More brain lesions, with more inflammatory cells, as seen on magnetic resonance imaging (MRI) scans; in contrast, people with PPMS tend to have more spinal cord lesions than brain lesions, with fewer inflammatory cells.
- Some people with RRMS develop SPMS, which entails a steady worsening of symptoms over time.

  Without treatment, the transition generally occurs after 10 to 20 years, but early, aggressive treatment may slow the progression.

Symptoms of RRMS

In the early stages of the disease, such symptoms as blurred or double vision, muscle weakness, stiffness, spasms, tingling and numbness in the limbs, coordination and balance problems, and fatigue are common.

Many people with RRMS notice that certain activities or situations, such as taking a hot bath or being under a lot of stress, seem to trigger flare-ups—periods of intensifying symptoms (also commonly referred to as relapses or exacerbations).

If damage to your central nervous system progresses with RRMS, you may develop health issues ranging from depression and mood changes to difficulties with memory and concentration, urinary urgency and frequency, bowel problems such as constipation, and sexual difficulties.

How people experience RRMS varies widely. Some have flare-ups, lasting anywhere from days to months before easing up, while others notice gradual but steady physical and cognitive decline over time. Still others live for years with only occasional, small reminders they have MS.

There's no way to predict what course the illness will take, but with the appropriate therapy, most people with MS don't become disabled, says Brian R. Apatoff, MD, PhD, associate professor of neurology and neuroscience at Weill Cornell Medical College and director of the Multiple Sclerosis Institute in New York City. "We have some amazing therapies."

The outlook is much better than it used to be, Dr. Apatoff notes. "Research in MS is one of the most active areas in the field of neurology, with several new therapies in the pipeline," he says. "MS is one of neurology's bright, shining areas of investigation." ■

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

EVERY
4 WEEKS
300mg IV
TYSABRI®
(natalizumab)

I fight with TYSABRI because I WON'T BE HELD DOWN

LYSA, TYSABRI Fighter for 8+ years

Discover a relapsing multiple sclerosis treatment with more than a decade in the fight

200,000+ fighters* have put TYSABRI in their corner. Learn more at FightingWithTYSABRI.com.

*Based on cumulative data of 202,300 patients who have taken TYSABRI globally as of September 2019.

Please see full Prescribing Information, including **Boxed Warning** on TYSABRI.com, and Medication Guide on following page, as well as Important Safety Information below.

What is TYSABRI® (natalizumab)?

TYSABRI® (natalizumab) is a prescription medicine used to treat relapsing forms of multiple sclerosis (MS), to include clinically isolated syndrome, relapsing-remitting disease, and active secondary progressive disease. TYSABRI increases the risk of progressive multifocal leukoencephalopathy (PML). When starting and continuing treatment with TYSABRI, it is important to discuss with your doctor whether the expected benefit of TYSABRI is enough to outweigh this risk.

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

IMPORTANT SAFETY INFORMATION

TYSABRI increases your risk of getting a rare brain infection—called progressive multifocal leukoencephalopathy (PML)—that usually leads to death or severe disability.

- There is no known treatment, prevention, or cure for PML
- You should not take certain medicines that weaken your immune system at the same time you are taking TYSABRI. Even if you use TYSABRI alone to treat your MS, you can still get PML
- Your risk of getting PML is higher if you:
  - have been infected by the John Cunningham Virus (JCV). JCV is a common virus that can cause PML in people who have weakened immune systems, such as people taking TYSABRI. Before or while you receive TYSABRI, your doctor may do a blood test to check if you have been infected by JCV
  - have received TYSABRI for a long time, especially for longer than 2 years
  - have received certain medicines that can weaken your immune system before you start receiving TYSABRI

Important Safety Information continued on the following page.

IMPORTANT SAFETY INFORMATION (CONT'D)

- Your risk of getting PML is greatest if you have all 3 risk factors listed at left. There may be other risk factors that have not yet been identified
- Patients who are anti-JCV antibody negative are still at risk for the development of PML due to the potential for a new JCV infection or a false negative test result. Therefore, patients with a negative test result should be retested periodically
- While you receive TYSABRI, and for 6 months after you stop receiving TYSABRI, it is important that you call your doctor right away if you have any new or worsening medical problems (such as problems with your thinking, eyesight, balance, or strength; weakness on 1 side of your body; and using your arms and legs) that have lasted several days. Tell all of your doctors that you are getting treatment with TYSABRI
- Because of your risk of getting PML while you receive TYSABRI, TYSABRI is available only through a restricted distribution program called the TOUCH® Prescribing Program

Who should not receive TYSABRI?

Do not receive TYSABRI if you have PML or are allergic to natalizumab or any of the ingredients in TYSABRI.

What should I tell my doctor before receiving each dose of TYSABRI?

Before receiving TYSABRI, it is important to tell your doctor:

- If you have a medical condition that can weaken your immune system, such as HIV infection or AIDS, leukemia or lymphoma, organ transplant, or others, or if you have any new or worsening medical problems that have lasted several days
- If you are pregnant or plan to become pregnant or if you are breastfeeding or plan to breastfeed. It is not known if TYSABRI can harm your unborn baby or if the TYSABRI that passes into your breast milk can harm your baby
- About all of the medicines and supplements you take, especially medicines that can weaken your immune system. If you are not sure, ask your doctor

What are the possible side effects of TYSABRI?

TYSABRI can cause serious side effects. If you have any of the symptoms listed below, call your doctor right away:

- **Herpes infections.** Increased risk of infection of the brain or the covering of your brain and spinal cord (encephalitis or meningitis) caused by herpes viruses that may lead to death. Symptoms include sudden fever, severe headache, or confusion. Infection of the eye caused by herpes viruses leading to blindness in some patients has occurred. Call your doctor if you have changes in vision, redness, or eye pain
- **Liver damage.** Symptoms include yellowing of the skin and eyes (jaundice), unusual darkening of the urine, nausea, feeling tired or weak, or vomiting
- **Allergic reactions (e.g., hives, itching, trouble breathing, chest pain, dizziness, wheezing, chills, rash, nausea, flushing of skin, low blood pressure), including serious allergic reactions (e.g., anaphylaxis).** Serious allergic reactions usually happen within 2 hours of the start of the infusion, but they can happen any time after receiving TYSABRI
- **Weakened immune system.** TYSABRI may increase your risk of getting an unusual or serious infection
- **Low platelet counts.** TYSABRI may cause the number of platelets in your blood to be reduced. Symptoms include easy bruising, small scattered red spots on your skin that are red, pink or purple, heavier menstrual periods than are normal, bleeding from your gums or nose that is new or takes longer than usual to stop, bleeding from a cut that is hard to stop

The most common side effects of TYSABRI are:

- Headache, urinary tract infection, lung infection, pain in your arms and legs, vaginitis, stomach-area pain, feeling tired, joint pain, depression, diarrhea, rash, nose and throat infections, and nausea. If you experience any side effect that bothers you or does not go away, tell your doctor

These are not all of the possible side effects of TYSABRI. For more information, ask your doctor. **To report side effects to FDA, please call 1-800-FDA-1088.**

Please see full Prescribing Information, including **Boxed Warning** on TYSABRI.com, and Medication Guide on following page.

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

Biogen

8/20 TYS-US-1500v4

225 Binney Street, Cambridge, MA 02142 • 1.800.456.2255 TYSABRI.com

EVERY 4 WEEKS 300mg IV TYSABRI® (natalizumab)

EVERY
4 WEEKS
300mg IV
TYSABRI®
(natalizumab)

MEDICATION GUIDE

TYSABRI® (tie-SA-bree)
(natalizumab) injection, for intravenous use

Read this Medication Guide before you start receiving TYSABRI and before you receive each dose. There may be new information. This Medication Guide does not take the place of talking to your doctor about your medical condition or your treatment.

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

- **TYSABRI increases your chance (risk) of getting a rare brain infection that usually leads to death or severe disability. This infection is called progressive multifocal leukoencephalopathy (PML). If PML happens, it usually happens in people with weakened immune systems.**
    - **There is no known treatment, prevention, or cure for PML.**
    - **Your chance of getting PML may be higher if you are also being treated with other medicines that can weaken your immune system, including other treatments for Multiple Sclerosis (MS) and Crohn's disease (CD). You should not take certain medicines that weaken your immune system at the same time you are taking TYSABRI. Even if you use TYSABRI alone to treat your MS or CD, you can still get PML.**
    - **Your risk of getting PML is higher if you:**
        - have been infected by the John Cunningham Virus (JCV). JCV is a common virus that can cause PML in people who have weakened immune systems, such as people taking TYSABRI. Before or while you receive TYSABRI, your doctor may do a blood test to check if you have been infected by JCV
        - have received TYSABRI for a long time, especially longer than 2 years
        - have received certain medicines that can weaken your immune system before you start receiving TYSABRI

      Your risk of getting PML is greatest if you have all 3 risk factors listed above. There may be other risk factors for getting PML during TYSABRI treatment that we do not know about yet. Your doctor should discuss the risks and benefits of TYSABRI treatment with you before you decide to receive TYSABRI. See "What are the possible side effects of TYSABRI?"
    - **While you receive TYSABRI, and for 6 months after you stop receiving TYSABRI, it is important that you call your doctor right away if you have any new or worsening medical problems that have lasted several days.** These may be new or sudden and include problems with:
        - thinking
        - balance
        - eyesight
        - weakness on 1 side of your body
        - strength
        - using your arms and legs

Tell all your doctors that you are receiving TYSABRI.

- **Because of your risk of getting PML while you receive TYSABRI, TYSABRI is available only through a restricted distribution program called the TOUCH® Prescribing Program.** To receive TYSABRI, you must talk to your doctor and understand the risks and benefits of TYSABRI and agree to follow all of the instructions in the TOUCH® Prescribing Program.
    - **TYSABRI is only:**
        - prescribed by doctors who are enrolled in the TOUCH® Prescribing Program
        - given at an infusion center that is enrolled in the TOUCH® Prescribing Program
        - given to people who are enrolled in the TOUCH® Prescribing Program
    - **Before you receive TYSABRI, your doctor will:**
        - explain the TOUCH® Prescribing Program to you
        - have you sign the TOUCH® Prescriber and Patient Enrollment Form

What is TYSABRI?

TYSABRI is a prescription medicine used to treat adults with:

- relapsing forms of Multiple Sclerosis (MS), to include clinically isolated syndrome, relapsing-remitting disease and active secondary progressive disease. TYSABRI increases the risk of PML. When starting and continuing treatment with TYSABRI, it is important that you discuss with your doctor whether the expected benefit of TYSABRI is enough to outweigh this risk. See "**What is the most important information I should know about TYSABRI?**"
- moderate to severe Crohn's disease (CD). TYSABRI is used:
    - to reduce signs and symptoms of CD
    - in people who have not been helped enough by, or cannot use the usual CD medicines and medicines called tumor necrosis factor (TNF) inhibitors.
- It is not known if TYSABRI is safe and effective in children under 18 years of age.

Who should not receive TYSABRI?

Do not receive TYSABRI if you:

- have PML
- are allergic to natalizumab or any of the ingredients in TYSABRI. See the end of this Medication Guide for a complete list of ingredients in TYSABRI.

Talk to your doctor before receiving TYSABRI if you have any of these conditions.

What should I tell my doctor before receiving each dose of TYSABRI?

Before you receive TYSABRI, tell your doctor if you:

- have medical conditions that can weaken your immune system, including:
    - HIV infection or AIDS
    - other medical conditions that can weaken your immune system
    - leukemia or lymphoma
    - an organ transplant
- have any new or worsening medical problems that have lasted several days. These may be new or sudden and include problems with:
    - thinking
    - strength
    - eyesight
    - weakness on 1 side of your body
    - balance
    - using your arms and legs

- have had hives, itching or trouble breathing during or after receiving a dose of TYSABRI
- have a fever or infection (including shingles or any unusually long lasting infection)
- are pregnant or plan to become pregnant. It is not known if TYSABRI can harm your unborn baby.
- are breastfeeding or plan to breastfeed. TYSABRI can pass into your breast milk. It is not known if the TYSABRI that passes into your breast milk can harm your baby. Talk to your doctor about the best way to feed your baby while you receive TYSABRI.

Tell your doctor about all the medicines you take, including prescription and over-the-counter medicines, vitamins and herbal supplements. Especially tell your doctor if you take medicines that can weaken your immune system. Ask your doctor if you are not sure.

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

How should I receive TYSABRI?

- TYSABRI is given 1 time every 4 weeks through a needle placed in your vein (IV infusion).
- Before each TYSABRI dose you will be asked questions to make sure TYSABRI is still right for you.

What are the possible side effects of TYSABRI?

TYSABRI may cause serious side effects, including:

- **See "What is the most important information I should know about TYSABRI?"**
- **Herpes Infections.** TYSABRI may increase your risk of getting an infection of the brain or the covering of your brain and spinal cord (encephalitis or meningitis) caused by herpes viruses that may lead to death. Call your doctor right away if you have sudden fever, severe headache, or if you feel confused after receiving TYSABRI. Herpes infections of the eye, causing blindness in some patients, have also occurred. Call your doctor right away if you have changes in vision, eye redness, or eye pain.
- **Liver damage.** Symptoms include:
    - yellowing of the skin and eyes (jaundice)
    - unusual darkening of the urine
    - nausea
    - feeling tired or weak
    - vomiting

  Call your doctor right away if you have symptoms of liver damage. Your doctor can do blood tests to check for liver damage.
- **Allergic reactions, including serious allergic reactions.** Symptoms of an allergic reaction can include:
    - hives
    - dizziness
    - nausea
    - itching
    - wheezing
    - flushing of skin
    - trouble breathing
    - chills
    - low blood pressure
    - chest pain
    - rash

  Serious allergic reactions usually happen within 2 hours of the start of your infusion, but they can happen at any time after you receive TYSABRI.

  Tell your doctor right away if you have any symptom of an allergic reaction, even if it happens after you leave the infusion center. You may need treatment if you are having an allergic reaction.
- **Infections.** TYSABRI may increase your chance of getting an unusual or serious infection because TYSABRI can weaken your immune system. You have a higher risk of getting infections if you also take other medicines that can weaken your immune system.
- **Low platelet counts.** TYSABRI may cause the number of platelets in your blood to be reduced. Call your healthcare provider if you have any of the following symptoms:
    - easy bruising
    - heavier menstrual periods than are normal
    - bleeding from your gums or nose that is new or takes longer than usual to stop
    - small scattered red spots on your skin that are red, pink, or purple
    - bleeding from a cut that is hard to stop

The most common side effects of TYSABRI include:

- headache
- lung infection
- vaginitis
- stomach area pain
- feeling tired
- depression
- rash
- urinary tract infection
- pain in your arm and legs
- nose and throat infections
- joint pain
- diarrhea
- nausea

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

These are not all the possible side effects of TYSABRI. Ask your doctor for more information.

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

General information about the safe and effective use of TYSABRI.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide.

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

For more information, go to www.TYSABRI.com or call 1-800-456-2255.

What are the ingredients in TYSABRI?

Active ingredient: natalizumab

Inactive Ingredients: sodium chloride, sodium phosphate, monobasic, monohydrate; sodium phosphate, dibasic, heptahydrate; polysorbate 80, and water for injection

Manufactured by: Biogen Inc.; Cambridge, MA 02142 USA

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

Revised 08/2020

TYS-US-1500v4

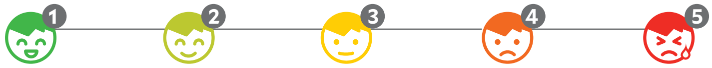
Doctor Discussion Guide:

RELAPSING MULTIPLE SCLEROSIS

Monitoring your symptoms and receiving the right care can make all the difference when managing your multiple sclerosis. You can take an active role in your health by not only asking questions, but also presenting your doctor with a complete picture of what you're experiencing. Toward that end, fill out the guide below so that you're prepared to have a detailed discussion with your doctor. Doing so will help your doctor to best help you.

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

Improved **Stayed About the Same** **Gotten Worse**



2. With fall and winter approaching, how will the colder temperatures affect my MS?

____
____
____

3. What adjustments should I make to ease my MS symptoms as the weather changes?

____
____
____

4. If I get the flu or a cold, how will that affect my MS?

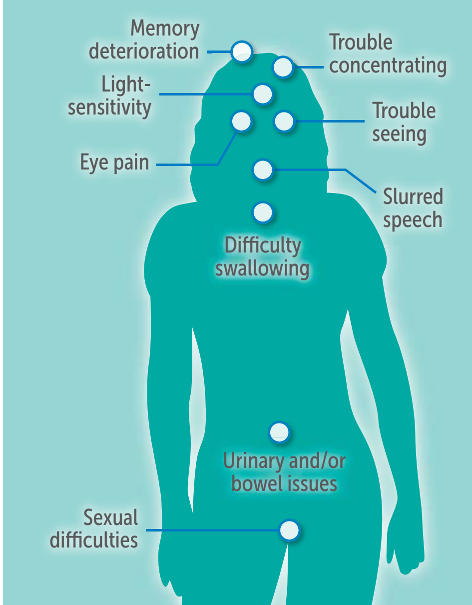
____
____
____

5. What activities, foods, or routines should I add to my day-to-day life to help me manage my MS?

____
____
____

Below are the symptoms I am experiencing:

(check all applicable areas)



○ Balance and coordination difficulties
○ Depression
○ Difficulty sleeping
○ Fatigue
○ Muscle weakness
○ Pain
○ Stiffness
○ Tremors (shaking)

HealthCentral.com/msguide

MSD3

healthcentral
LIVE BOLD • LIVE NOW

YOUR DREAM TEAM

Here are some of the specialists you may be working with:

- **NEUROLOGIST:** A doctor who focuses on brain and nerve conditions; ideally, you'll see one who specializes in MS.
- **SOCIAL WORKER:** Helps with work, disability, and other services
- **PSYCHOLOGIST OR COUNSELOR:** Helps with emotional issues and personal challenges related to MS
- **NEUROPSYCHOLOGIST:** Deals with psychological concerns that arise due to neurological changes from MS
- **NUTRITIONIST:** Recommends optimal dietary choices
- **PHYSICAL AND OCCUPATIONAL THERAPISTS:** Help you maintain the skills you need for daily life and work

Take the Lead

Updating your doctor on your symptoms is key for successful treatment.

When you're living with multiple sclerosis, your condition may change over time, so your treatment needs may change, too.

But because MS symptoms often fluctuate from day to day, and office visit to office visit, tracking the progression or slowing of the disease is complicated. The best way for you and your doctor to know how well you are responding to your current treatment plan is by spending some time with each other at regular office visits.

Your physician will probably want to see you every three to six months in the first one or two years after your diagnosis. After that, you'll most likely visit your doctor every six months or once a year. Be sure to keep up with the recommended appointment schedule, and check in between visits if you're having any new symptoms, medication side effects, or other issues. Monitoring your health over time, getting essential tests, and having your treatment adjusted as needed can make all the difference in living with MS.

What's That Test?

To measure MS progression and your response to treatment, your doc may give you some of the following tests:

- **Magnetic resonance imaging (MRI):** This technology produces highly detailed images of your body. With an MRI of the brain and spinal cord, doctors can spot lesions characteristic of MS, as well as other changes.
- **Neurological exam:** Your physician will check your reflexes, coordination, gait (how you walk), and balance.
- **Vision:** It's not uncommon for people with MS to experience blurred or double vision, so your doctor will look for optic nerve damage.
- **Other senses:** Some people with MS lose part or all of their ability to taste or smell, develop hearing troubles, or have problems with their ability to feel pain and other sensations. Since such issues can indicate progression of the disease, your doctor will sometimes test these senses.
- **Cognitive function:** MS can affect the way your brain works, so you may have tests that evaluate speech processing, working memory, reasoning and planning, visual perception, and language. ■

MAKING THE MOST OF YOUR OFFICE VISITS

1. SEE AN MS SPECIALIST if you can. Check with the National MS Society (**nationalmssociety.org/Resources-Support/Find-Doctors-Resources**) or the Consortium of Multiple Sclerosis Centers (go to **mscare.org** and click on MS Centers Directory under Connect) to find one.

2. TRACK CHANGES in your health (positive and negative). Using a journal or app, regularly record anything new going on between appointments. This makes it easier to recognize problems as they occur. Bring your notes to all of your health-care appointments.

3. BE AWARE of new or changing symptoms that may indicate your MS is progressing, including vision issues, vertigo, limb weakness or numbness, poor balance or coordination, falling, trouble walking or talking, memory loss, fatigue, and bladder or bowel problems.

4. DON'T WAIT for an appointment if you think you're having a flare-up. Call your neurologist. Sometimes the best way to stop a flare is through immediate therapy. Other times, you may just need to ride it out. You and your doc can decide on the best approach for you.

ISTOCK (2)

LIVE BOLD LIVE NOW™
STORIES THAT INSPIRE

Spinning tunes on Twitch gives Cohen an outlet for her love of music and for raising awareness about multiple sclerosis.

Finding Harmony

No longer able to play an instrument, Chloe Cohen discovers a different way to make music—and comes to embrace what MS has taught her.

Music had always been a huge part of **Chloe Cohen**'s life. She learned to play the piano at age 5 and the cello at 8, and continued playing throughout high school, winning awards along the way. But in May 1998, at age 20, Cohen received news that brought her budding music career to a halt. It would take years after a diagnosis of multiple sclerosis for her to find a way to make music again.

The talented musician, who grew up in St. Louis, Missouri, had been experiencing occasional numbness and tingling in her feet. In 1996, she moved to Colorado to attend college, but soon started experiencing extreme fatigue and sleeping through classes. After barely four months, she returned home to attend a community college. Then one day, she hit her head hard on a car door. Later, when her left arm and leg started to shake, she assumed it was related and would go away.

But her roommate, an ER nurse, told Cohen she didn't think the tremors were normal, and Cohen's mother took her to a neurologist. After an MRI and more doctor appointments, Cohen was told that she either had a brain tumor or multiple sclerosis. Given the choices, "at first, it was a relief to hear that it was MS," recalls Cohen, now 42. "But then I was like, 'Why me?'"

Life Without Music

After her diagnosis of relapsing-remitting MS, Cohen was put on an injectable drug meant to slow the progression of her disease. But there weren't many medications available

PHOTOS COURTESY OF CHLOE COHEN

back then, she says. "Even on the medication, I couldn't play the piano because my arm was shaking constantly," she says. "And I couldn't play the cello because I couldn't hold my fingers on the fingerboard."

Cohen had to drop out of community college because she was sleeping most of the day. "And my walking was off, so it almost looked to others like I was drunk," she says. She also had a tremendous fear of needles, and for a while, her roommate and then her father had to give her injections, which were only somewhat effective. "I had no balance or coordination," she says. "I had a tremor on my left side and three episodes of horrible double vision. I didn't know how to get through it, but I just kept pushing because I don't give up."

For Cohen, the physical effects of MS were proving hard to live with, but by far the more devastating consequence was losing her ability to play an instrument. "My passion is music, it's how I let out my emotions," she says. "When I couldn't express myself with music anymore, it threw me into emotional turmoil."

Back in the Groove

In 2000, Cohen moved to Portland, Oregon, where a good friend lived, and began attending Portland State University. Still missing the solace of playing an instrument, she started searching for a way to bring music back into her life. An old turntable from her high school days helped her do just that—by becoming a DJ.

"I bought another turntable, and that changed everything," she says. "It wasn't as tactile as playing an instrument, but I created all these electronic ways to make music. As I got better, I found more and more ways to manipulate the sound from the turntable. And that's what brought my musicianship back."

She made it through college, graduating in 2004 with a degree in speech communications, a major she had decided to pursue so she could learn to communicate effectively about MS. "I just knew I had a voice and wanted to speak to let people with MS see life through a different lens," she recalls.

Cohen has found purpose in advocating for people with MS.

Cohen started volunteering for the National Multiple Sclerosis Society, for which she is now an ambassador. In this role, she speaks on behalf of the society at various events. Two years ago, she participated in a public policy conference in Washington, DC, and talked with legislators about issues facing people with MS.

In 2005, seeing a tremendous need for individuals with MS to share their stories, she founded a support group in Portland. Initially intended for younger people living with MS, it became so popular that she opened it up to all age groups. "We call it the MS Rogue Happy Hour Group," she says. "We're like family."

Since the pandemic began, monthly meetings have been conducted online, and there's an active Facebook page available (**facebook.com/groups/244347412323807**).

In 2006, Cohen became an online DJ as a hobby, which meant that she could have an audience—and she loves sharing music with others. She could also sit during a session, important because standing for long periods would leave her feeling weak and cause a loss of balance and coordination. "When I first got started as a DJ, I had video and audio so that people could watch me and hear the music," she says. "I mostly did it on chat programs that allow video. Even today, I will just ask online if people want to hear me spin and if I get a thumbs-up, I do it."

As an online DJ, Cohen has been streaming live video on Twitch (**twitch.tv/djccboom503**). She's planning a fundraiser and awareness campaign called "Stream to End MS" on the site this fall.

Triumph Over Adversity

Three years ago, Cohen started on a new disease-modifying therapy. Since then, she says she's never felt better in terms of her energy. "I can run, I can jump, and I can do things that I never would have done before," she says. "I appreciate my body, and I don't take advantage of it. I recognize my physical limitations."

Cohen stays active by working out twice a week with a trainer. She gets together regularly with her sister, who lives in Los Angeles, to listen to music. She's even published a book, *Stronger Together*, about her journey with MS.

For now, Cohen feels good. "My fatigue is gone, my tremor is minute, and my balance is amazing after years of hard work," she says.

Being a DJ and immersing herself in music has helped Cohen remain optimistic about her future. Despite what she's lost, she recognizes what living with the illness has taught her.

"MS has given me so much more than it has taken away," Cohen says. "It's given me a perspective that most people don't have by the time they are 30. When you have MS, you learn to appreciate things. Most people don't know how to do this until they're 60 or 70. I'm just 42, and there's not a day that goes by that I am not grateful for being able to walk and to see." ■

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

What Are My Options?

Your doctor will help you weigh the benefits and risks of MS treatments.

Thirty years ago, not a single drug was approved to treat MS. Today, there are close to 20 meds for relapsing-remitting MS (RRMS). Many of these are also approved for other forms of the disease.

That's good news, but the range of choices can make planning MS treatment a little complicated. Your doctor will consider the nature and severity of your illness, along with your specific symptoms, to determine which medication is best for you.

Treatments known as disease-modifying therapies (DMTs), which focus on slowing the course of the disease, are a key part of MS care. DMTs can't cure the condition, but they can moderate the accumulation of lesions in the brain and spinal cord while lessening the frequency and severity of attacks. They can also help delay the progression of disability. DMTs can be injected, given via intravenous (IV) infusion, or taken orally (see sidebar).

Your treatment plan may also involve medications aimed at controlling symptoms of MS, such as fatigue, depression, muscle stiffness and spasms, and bladder and bowel problems. There are a few nondrug therapies that have been shown to help ease certain symptoms as well.

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

Like many things in life, there is no one-size-fits-all treatment approach for MS, and finding what works best for you may require a bit of trial and error. Try not to get discouraged if it takes a few attempts before a match is made. With so many options available, eventually something will click. ■

DMT TYPES

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

INFUSIONS: The DMTs administered via IV infusion are alemtuzumab (Lemtrada), mitoxantrone, natalizumab (Tysabri), and ocrelizumab (Ocrevus). Depending on the medication, infusion time can range from as little as five minutes to several hours, and infusions are repeated anywhere from daily to yearly for varying periods of time. The side effects differ by drug, so be sure to ask your doctor about those.

ORAL MEDS: The DMTs taken as pills include dimethyl fumarate (Tecfidera), fingolimod (Gilenya), and teriflunomide (Aubagio). Newer oral medications are siponimod (Mayzent), cladribine (Mavenclad), ozanimod (Zeposia), diroximel fumarate (Vumerity), and monomethyl fumarate (Bafiertam). Like most meds, oral drugs have side effects and risks. Work with your doctor to choose your best option.

ISTOCK (4)

Best of the Blogs

Looking for support and encouragement? These online writers living with MS share their experience, wisdom, and hope.

Dave Bexfield

Barbara Stensland

Caroline Craven

Willeke Van Eeckhoutte

Nicole Lemelle

■ "There likely will be times with multiple sclerosis that you fail trying to do something that the old you could do effortlessly. It's important to realize that's OK. Heck, when you have MS, failure absolutely is an option—and an important one. Because if you never try, if you never experiment, if you never leave your comfort zone, then this disease wins. Screw that."

—Dave Bexfield
(activemsers.blogspot.com)

■ "Life has been honed down toward what is most important, and that's been a huge learning curve. I've discarded all thoughts of what I should be doing, could be doing, ought to be doing. I now choose. So yes, MS happened. It's not the best, it never will be, but I will try for as long as I can to continue to be the best parent I can, above everything."

—Barbara Stensland
(stumblinginflats.com)

■ "Today my emotions are way over-the-top upset, and there's no denying that I really despise my MS right now. But the angrier I get, the more worked up my MS becomes. This isn't productive or healthy for anyone. Time to force a change! Seek out something beautiful in life: A sit in the garden. A chat with a friend. A stroll through the neighborhood. Find the beauty, grace, and appreciation that is the basis of life. Just sitting out in the garden for a few minutes can help."

—Caroline Craven
(girlwithms.com)

■ "Love yourself, even when your outlook on life and your appearance have changed because of your illness. You know that you—and your illness—are real. You know the physical pain you have learned to hide, even when it feels like being hit by flashes of lightning. You know how long it took to be diagnosed with MS. And you know that you are 100 percent precious. Don't let anyone steal your sunshine."

—Willeke Van Eeckhoutte
(irelandms.com)

■ "Love has always been my guide. It channels me to memories of all the people I have met at my local MS support group. They always welcome me with hugs and kisses. I think about the social media posts of people who are just like me—and who strive despite the odds. They understand my plight. They help me remember I am not alone."

—Nicole Lemelle
(mynewnormals.com)

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

MEDICAL EDITORS: **Brian R. Apatoff, MD, PhD,** director, Multiple Sclerosis Institute; clinical attending in neurology, NewYork-Presbyterian Hospital; and associate clinical professor of neurology and neuroscience, Weill Cornell Medical College, New York City; **Shaheen Lakhan, MD, PhD,** vice president, research and development, the Learning Corp, Newton, MA.

HEALTHCENTRAL GUIDE MEDICAL EXPERTS: **Aaron Miller, MD,** professor of neurology, Icahn School of Medicine, and medical director, Corinne Goldsmith Dickinson Center for Multiple Sclerosis, Mount Sinai Hospital, New York City; **Amber Salter, PhD, MPH,** assistant professor of biostatistics, Washington University, St. Louis, MO; **Robert Glenn Smith, MD, PhD,** neurologist, Houston Methodist Hospital, Houston, TX; **Vijayshree Yadav, MD,** associate professor of neurology, Oregon Health & Science University School of Medicine, Portland.

REMEDY HEALTH MEDIA: **Julia Savacool,** deputy editor; **Linda Roman,** editor; **Rosemary Black, Stacey Colino, Beth Howard,** writers; **Patricia Volin,** fact-checker; **Hallie Einhorn,** copy editor; **Douglas+Voss,** designers.

Remedy Health Media websites: **HealthCentral**, **TheBody**, **TheBodyPRO**, **Berkeley Wellness**, **Psycom**, **EndocrineWeb**, **Practical Pain Management (PPM)**, **SpineUniverse**, **OnTrack Diabetes**, and **OBR Oncology**. Print publications: *Health After 50*; the *University of California, Berkeley, Wellness Letter*; and medical condition white papers.

ALL PHOTOS COURTESY OF INDIVIDUAL SUBJECTS