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# MS Perspectives™

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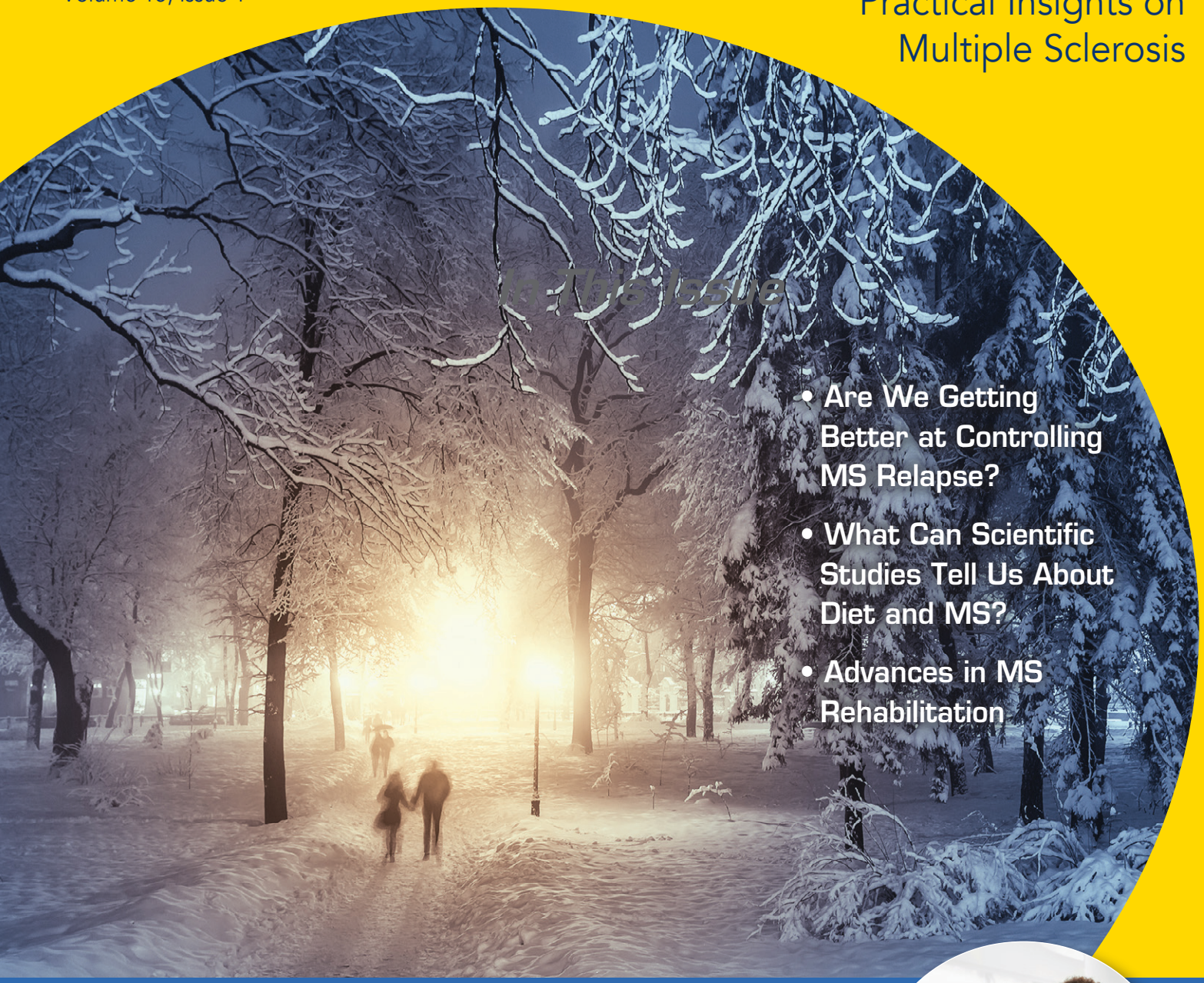
Practical Insights on Multiple Sclerosis



In This Issue



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# Are We Getting Better at Controlling MS Relapse?

The tell-tale signs of a relapse coming on—such as weakness, numbness, or worsening balance problems—are never a welcome sign for a person with MS. Ideally, a person with MS would experience few or no acute relapses, especially if one is taking a disease-modifying therapy (DMT). "Newer therapies, such as B-cell therapies and other infusions, have reduced the occurrence of MS relapses, which is a primary goal in MS along with reduction of disability. I see more pseudo-relapses than true relapses in my practice due to the effective newer therapies" says Aliza Ben-Zacharia, PhD, DNP, ANP, FAAN, who has an independent MS practice in New York City. "Unfortunately, we can never guarantee that relapses can be completely avoided. None of the therapies prevent relapses at 100%. However, a few of the medication reduce the risk of relapses by 60%."

## What is an MS relapse?

An MS relapse represents an episode of increased disease activity. Inflammation in the brain and spinal cord is "switched on" and actively causing demyelination. Relapses may also be called exacerbations, flares, attacks, or acute episodes of MS. For people with relapsing MS (RMS), the disease spends much time in remission. During remission, MS symptoms are often relatively stable without obvious worsening. When a true relapse occurs, new or worsening symptoms usually appear and may persist after recovery from the relapse.

The National Multiple Sclerosis Society (NMSS) defines MS relapse as, "the occurrence new symptoms or the worsening of old symptoms. It can be very mild, or severe enough to interfere with a person's ability to function." (**See Figure 1, Definition of an MS Relapse**.)

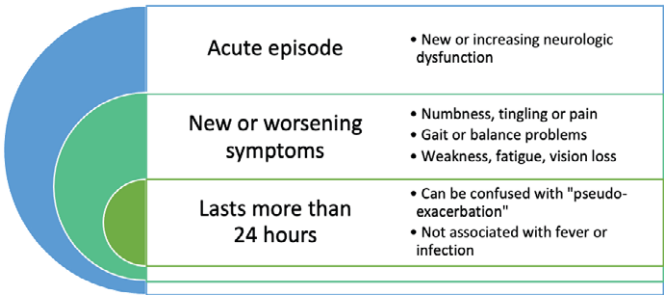
## What is happening in the brain and/or spinal cord during an MS relapse?

Relapses are the outward manifestations of a spike in inflammatory activity. Relapses may represent a new break in the blood-brain barrier. This

**Disclaimer:** The goal of this publication is to provide patients with multiple sclerosis with the latest information about the disease and its treatment. The information provided in *MS Perspectives™* is not a substitute for the advice of your healthcare nurse or doctor. Please consult a qualified healthcare provider for individualized care and information.

Cover photo credit: ©beerlogoff / iStock

## Figure 1. Definition of an MS Relapse




Source: National Multiple Sclerosis Society (NMSS). Relapse management. Available at: http://www.nationalmssociety.org/For-Professionals/Clinical-Care/Managing-MS/Relapse-Management.

is a network of blood vessels and tissues that separates the blood of the brain and spinal cord (the central nervous system or CNS) from the rest of the bloodstream. Through this break, immune cells can travel into the CNS. This includes some cell types that damage myelin, the protective coating of the nerve cells that becomes damaged in MS and the axons (nerves), which occurs early in the disease course. When the relapse is over, many people do not fully recover the same function they had before the relapse. Studies suggest that people with MS accumulate some degree of functional change after each relapse.

### *Is this really a relapse? Some clues*

There is a saying about MS relapse: It's hard to describe, but you know it when you see or feel it. Many people with MS are able to detect early signs of a relapse and distinguish between it and other health issues. But for some, the early warning signs are not always so clear-cut. A "pseudo-relapse" is a change in MS symptoms that is not due to a demyelinating episode. It may be related to an infection or illness (**see Figure 2, Relapse vs Pseudo-relapse**).

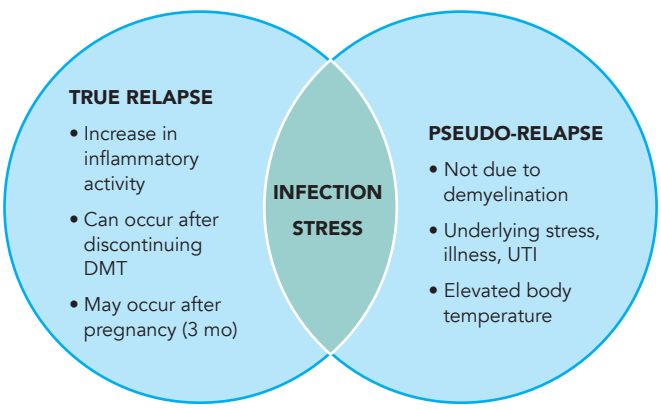
### *Talking to the healthcare provider*

Some signs or symptoms may fall into a gray area, in the sense that they could occur in the presence of either a true relapse or a pseudo-relapse. If you think you may have a relapse starting, it is essential that you contact your MS healthcare provider to arrange a phone conversation, video call, or in-person visit, based on what he or she recommends. Some of the issues you might discuss with your healthcare provide include:

- What new signs/symptoms am I experiencing?
- When did I first notice these changes?
- Prior to these changes, how was I feeling?
- How have these symptoms affected my lifestyle (e.g., ability to work, take care of children, sleep)?
- Any recent viral infections I may have had
- Is there fever present?
- Are there any bladder symptoms such as urgency or frequent urination?
- Are there any areas of skin breakdown?
- Is there evidence of cellulitis (areas of redness, swelling, warmth on skin)?
- Could there be a dental abscess or infection?

If you experience new symptoms that interfere with your ability to function, this likely signals the need for immediate evaluation and potentially treatment. Even signs of a milder relapse should be reported to a healthcare provider. Your clinician may decide that you would benefit from a course of steroid treatment, but there also may be other treatments or self-care steps to follow. And, if you recover from this even with minimal effect on your overall functioning, the relapse may be a sign that a change in DMT may be warranted.

## Figure 2. Relapse vs Pseudo-relapse




### *Do I need a new MRI?*

Magnetic resonance imaging (MRI) is not required to diagnose a relapse. An MRI may be ordered during or after recovery to evaluate disease status. Also, if certain severe complications are suspected, MRI can be essential to rule out such conditions. If an MRI test with enhancement is done during an MS relapse, it may show the presence of new enhancing brain or spinal cord lesions.

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## Role of Urinary Tract Infections in MS Relapses

It is important to rule out the possibility of urinary tract infection (UTI) when relapse symptoms appear. UTIs are common in people with MS and are often thought of as the biggest culprits for mimicking a true relapse. Recurrent UTIs are often due to urinary stasis or catheter use secondary to bladder dysfunction. If a UTI goes untreated, it may lead to a more serious infection. UTIs may increase existing MS symptoms and therefore mimic a relapse. However, a UTI also may trigger a true relapse.

Treatment with a corticosteroids during relapse might make it harder to diagnose a UTI with a simple paper dipstick method. Your healthcare provider might elect to send out a urine sample for analysis, or start an antibiotic if an infection is suspected.

## Treatment for MS Relapses

A short course of high-dose corticosteroids is usually recommended to treat moderate or severe relapses (involving vision loss, severe weakness, poor balance, and/or interfering with a person's mobility, safety, or overall ability to function). Steroid treatments reduce inflammation and help the relapse to end more quickly.

- The most common treatment for relapse is a 3-day or 5-day course of intravenous (IV) methylprednisolone (often known by the brand name Solu-Medrol®). Another option is an oral prednisone. Some studies have shown that oral and IV steroids have similar effects. Side effect rates may be higher with oral steroids.
- For certain people who cannot tolerate these corticosteroid treatments, H.P. Acthar Gel is another possible option. This treatment uses a different hormone called an adrenocorticotropic hormone (ACTH).

Although hospitalization was once considered necessary for managing an MS relapse, today many MS clinicians try to avoid hospitalization unless the patient's relapse is severe enough to require rehabilitation afterward. Hospitalizations are costly and may not be fully covered on the patient's insurance plan.

## Impact of MS Relapses on the Patient and the Disease Course

The occurrence of a relapse can bring on a sense of anxiety for a person with MS. Relapses are a sign that the disease continues to be active. It may take 6 months or longer to determine how much recovery will occur after the relapse. Relapses often trigger a conversation between the patient and the clinician to reevaluate the current DMT. Is the treatment the most appropriate choice at this time? You might also discuss with your clinician how you are using the medication, and whether any doses have been missed.

## Conclusion

Relapse is only one way to determine if MS is active (see Box, Scientific Advances). However, dramatic reductions have been seen in relapse risk due to improved therapies and earlier treatment of MS. This represents a substantial advance in MS treatment overall. "Individualized care and effective MS treatments are essential to prevent relapses and to guarantee the highest well-being to people with MS," Dr. Ben-Zacharia says.

## How have scientific advances affected relapse rates?

Since MS DMTs have become available, relapse rates have continued to drop overall among people with relapsing forms of MS. Because there are many DMT choices, it is usually possible to select a therapy that works well for an individual. Ideally, this should be the most effective therapy for that person. Other factors that are important are:

- Comfort with how the drug is administered (oral, injection, infusion)
- Side effects are minimal and can be managed
- The drug treatment is affordable

Some of the older, injectable MS therapies like interferons reduced annual relapse rates by about 30%, compared with trial participants who took a placebo (no treatment). Instead of placebo, newer trials usually compare the study drug with another MS DMT (an injected interferon or a daily oral treatment). High-efficacy therapies usually provide a greater reduction in relapse rates.

Clinical trials of these agents typically show about a 46% to 50% reduction in relapse rates versus the comparison drug. These figures depend much upon how the drug is studied, how early therapy is started, and how active the patient's MS may be.

Beyond relapse, many other factors go into determining how well a drug is working, including its effect on disease progression. A major focus of MS research now is understanding how MS can cause unseen damage even when relapses are not occurring.

# WHAT DO THE LATEST SCIENTIFIC ADVANCES TELL US ABOUT THE ROLE OF DIET IN MS?

Can following a specific diet help control your multiple sclerosis (MS) symptoms? Promises of cure-all diets for a variety of diseases are common in books and on the internet. Unfortunately, much of the dietary advice available online and elsewhere is not based on scientific evidence. In these diets, consumers are often fed confusing messages about what *not* to eat. In reality, better nutrition should involve adding a greater variety of healthy foods. Eating a balanced diet (unprocessed carbohydrates, heart-healthy fats, and lean protein) helps to promote energy and enhance optimal health. "Diet is about maximizing nutrition and quality so your body functions at its best ability," advises Barbara Bishop, MS, ANP-C, MSCN, CNRN, an MS nurse practitioner at Bon Secours Mercy Neurology Clinic in Mechanicsville, Virginia. "It's more about changing your lifestyle than just 'going on a diet.'"

The impact of diet on MS is an important and ongoing research subject. So far, the scientific research has not identified a nutritional program that can directly slow or reverse the disease process in MS. However, improving the diet can influence a person's overall health in many ways. These include limiting obesity and diabetes, and helping to support other lifestyle changes such as improved sleep and exercise habits. These factors, in turn, can influence how MS affects the body. When we think about diet we often tend to focus mainly on our weight. But diet quality also affects mood, energy levels, and risk for conditions like high blood pressure. Among the general population, people who consume a healthier diet tend to have lower levels of pain, fatigue, depression, and cognitive difficulties.

## MS Diet Survey Findings

In 2015, nearly 7,000 people with MS completed an extensive survey about their diets. The survey participants were part of the North American Research Committee on MS (NARCOMS) registry. The questionnaire asked about their intake of fruits and vegetables, whole grains, and sugar, and other eating patterns.

Diets of survey participants rated as highest quality (Group 5) had the following features:

- Higher in fruits, vegetables, and legumes (average 3.3 servings per day)
- Higher in fiber and whole grains (average 1.7 servings per day)
- Higher in calcium
- Lower in red meat and processed meats (such as packaged lunch meats)
- Lower in sugar from desserts and sweetened beverages

Survey participants were asked whether they had a relapse of MS symptoms or a gradual worsening of symptoms in the past six months. They were asked to rate the severity of symptoms such as fatigue, mobility problems, pain, and depression.

Not surprisingly, the survey results suggested that people with healthier eating habits also tended to live healthier lifestyles: they were less likely be overweight or smokers, and more likely to engage in physical activity. Consuming a healthier diet and engaging in healthier habits had a significant impact on how they experienced symptoms of MS.

- People with the highest-quality diets were 20% less likely to have more severe physical disability than those with poor diets.
- Those with healthier overall lifestyle habits were less likely to report that they experienced severe fatigue, depression, pain, or cognitive impairment

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- MS symptom severity was reduced among those survey participants who were non-smokers, especially if they consumed better-quality diets.

MS-specific diets like the Sparks diet (low in saturated fat) and the Wahls diet (a modification of the Paleo or "cave man" diet) were followed by only 1% to 5% of those surveyed. Most did so to help manage their MS. In this research study, the numbers of participants in the MS-specific diets were too small to draw any clear conclusions about their effectiveness.

### *What about the Gut?*

Increasing interest has focused on how the gut microbiome affects the risk of getting MS and the overall disease course. About 80% of the immune system resides in the gastrointestinal (GI) tract, or the "gut."

Many researchers believe the gut is one place to look for answers about underlying causes and possibly even new treatments for MS. The role of the gut as the main headquarters of the immune system is not fully understood. However, scientists are beginning to gain more knowledge about the interactions between the microbes of the body, the foods and nutrients we consume, and the behavior of the immune system as it affects conditions such as MS.

"Scientific evidence is mounting a diet that influences a healthy microbiome in the gut might ultimately influence outcomes of chronic diseases, including MS," nurse practitioner Barbara Bishop explains. "Diet is not the only answer, but it may be part of the equation for helping to control chronic disease and associated symptoms."

If the gut microbiome could be off balance, can taking a probiotics or prebiotic help to set it right? There are ways to alter the bacteria in the microbiome, but exactly how to do that in people with MS remains unclear. Studies using a medical-grade probiotic have shown some immune system changes thought to be beneficial in MS. This suggests that there may be a way to modulate the immune system using probiotics, but we still don't have enough information to establish which probiotics should be used, at which doses, and what their impact might be.

"I advise patients to try to choose foods that support a healthy gut," Ms. Bishop says. "This sometimes includes foods containing probiotics, if appropriate. I stress more farm-to-table food sources when possible, and a major reduction in processed foods. All of this helps to properly feed the cells of our bodies to maximize our best state of health," she adds. "Eating the 'right foods' over a longer time period can help to stabilize or improve energy levels and sleep cycles. This is definitely part of the equation to managing chronic health issues in people with conditions like MS."

# Advances in MS Rehabilitation Can Help People at All Ability Levels

Can rehabilitation help to improve function in people with multiple sclerosis (MS)? Many MS centers have adopted advanced rehabilitation methods in recent years. Newer approaches in MS are borrowing from other areas like stroke and spinal cord rehabilitation, using modern technology like robotics, and even using exercise in different ways to expand functional abilities that have been limited by MS. "Rehabilitation is a key principle in the management of many chronic illnesses," says Aliza Ben-Zacharia, PhD, DNP, ANP, FAAN, who has an independent MS practice in New York City. "Through rehabilitation, we can work to restore and improve daily function among patients with these conditions, including MS."

## Applying Stroke Rehabilitation Methods in MS

Rehabilitation methods that are successful in restoring movement after a stroke are being applied for people with MS. Research on stroke rehabilitation has advanced greatly in the past two decades, based on the concept of "neuroplasticity." This refers to the brain's potential ability to reorganize its neural "wiring" after damage and regain lost function. Some stroke rehabilitation methods focus on relearning "task-specific" skills, such as using a fork, reaching for objects, or typing, by repeating the task over and over. Studies in people with stroke have shown that this task specificity—doing the task you want to train for—can be beneficial to help relearn lost abilities.

Stroke differs from MS in many ways, says Dr. Ben-Zacharia. Both involve damage to nerve tissue in the central nervous system (the brain and the spinal cord), but MS involves an ongoing and progressive process. It is important that rehabilitation techniques be tailored for the individual in a timely manner. "For some people, a part of the body such as an arm or a leg, may have been immobile or nonfunctional for a long period, therefore these rehabilitation approaches may not make an impact."

## Robotics and MS Rehab

An advanced rehabilitation technology involves a wearable robotic device called an "exoskeleton." This device has a harness that is worn across the chest, with straps extending around the body and down the legs. Sensors on the device can detect changes in balance and motion. While wearing the device, the user shifts his or her weight to activate the sensors in the leg. A therapist can also activate the sensors. Battery-operated motors control movements of the hip and the knee to help the user initiate a step. In addition to being used in research, these devices are now approved by the Food & Drug Administration (FDA) for use in persons with MS as well as spinal cord injury, stroke, and chronic brain injury. In centers such as the Cleveland Clinic, people with MS who have severe gait impairment have been able to improve their walking speed, posture, and overall mobility after working with the device regularly.

## Exercise to Restore Function—Powerful When Used Correctly

The benefits of exercise in people with MS at all levels of disability have become more widely accepted in recent years. Research in MS shows that exercise stimulates all body systems to adapt and grow stronger over time, including the brain and central nervous system. These principles are not limited to people who are already physically active. People with MS who use wheelchairs or assistive devices can also benefit from specially modified exercise programs, in ways that can

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### MS News, Support, and Self-Help Groups

**Consortium of Multiple Sclerosis Centers**
www.MScare.org

**Can Do Multiple Sclerosis**
www.mscando.org

**MS Views & News**
http://www.msviews.org/msviewsandnews4

**MS World**
www.msworld.org

**Multiple Sclerosis Association of America**
http://mymsaa.org, 800-532-7667

**Multiple Sclerosis International Federation**
www.msif.org

**Multiple Sclerosis Foundation**
www.msfocus.org, 888-MSFOCUS (888-673-6287)

**National Multiple Sclerosis Society**
www.nationalmssociety.org, 800-344-4867

## ADVANCES IN MS REHABILITATION (Continued from page 7)

eventually help to restore function. This might include arm cycling (similar to regular cycling except the arms are used to pedal) or resistance training using bands or Velcro type weights. In a rehab center, this could also involve cycling exercises aided with electrical nerve stimulation, or walking on a treadmill while the body weight is supported in a harness.

The most common forms of physical training used in MS centers are aerobic exercise, progressive resistance training, stretching, balance training, and respiratory training. These programs are designed to increase limb power, walking speed and endurance, and overall physical fitness. However, in the "real world" outside of specialized rehab facilities, it can be much more difficult to maintain a regular exercise program. The ideal exercise program for any individual is one that they are:

1) willing to do
2) comfortable doing or can grow more comfortable over time
3) able to do regularly

"I always encourage my patients with MS to find an activity that fits their lifestyle and one that they may enjoy doing on a regular basis. This can be walking, swimming, using a stationary bike or elliptical machine, or other activities. In addition, it is important to get an approval from your MS team for any physical activity that you would like to initiate. This is for your safety and overall effectiveness of the activity," advises Dr. Ben-Zacharia.

See the box below for some resources to help you incorporate movement and exercise into your daily life.

# Finding the Right Exercise For You: Community and Online Resources

### Local NMSS Chapter Resources

Check your local National Multiple Sclerosis Society (NMSS) chapter for physical activity program offerings in your area. These can range from YMCA-based programs designed specifically for individuals with MS, tai chi and yoga courses, recumbent or adaptive cycling, horseback riding, and adventure trips.

### Online Exercise Programs Designed for MS

For some basics, check out the Cleveland Clinic video, "Exercises for Individuals with MS. Warm-up, Strength, Core and Balance." Available at: https://www.youtube.com/watch?v=X8nkMFcBIvA

### Wheelchair Exercise Resources Online

UK MS Society Wheelchair Exercise Video Search: Youtube/MS Active Together Series/Move More With MS

SpecialStrong. Top 10 Exercises for People in Wheelchairs. Available at: https://www.specialstrong.com/exercises-for-people-in-wheelchairs/

### Explore how these activities might fit or be adapted to your needs

***Yoga***

Yoga can help relieve MS symptoms such as stiffness, fatigue, and pain. Many yoga classes can be adapted for those with mobility limitations or spasticity. An added advantage of yoga is helping to control stress and anxiety.

***Pilates***

Pilates focuses on gaining strength in the body's core: the abdomen, obliques, trunk, and groin/buttocks area. These low intensity movements can be adapted for any age or ability level, with an instructor's help or using online programs. Added benefits of core strengthening can include improved bowel and bladder control.

***Aquatic exercise***

Exercising in water may help you move in ways you had not thought possible. The flotation encourages muscle relaxation, while the water's resistance gradually improves muscle strength and balance. High heat can be problematic for some people with MS, so exercising in cooler water might be preferable. The National Multiple Sclerosis Society (NMSS) recommends water temperatures of 80 to 84 degrees.