

MS EMPOWERMENT SERIES

SHARED DECISION MAKING IN MULTIPLE SCLEROSIS



STAYING ACTIVE AND HEALTHY WITH MS

*How to Find the Best
Fitness Options For You*



An educational series for people with multiple sclerosis (MS) developed in conjunction with the International Organization of MS Nurses (IOMSN)

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“I have witnessed a significant impact from exercise in people with all stages from MS, from those with milder disease to people with more advanced MS. To some extent, this theory applies for all of us: the more you do, the more you can do.”

— SHARON LYNCH, MD
DIRECTOR, UNIVERSITY OF KANSAS
CENTER FOR MULTIPLE SCLEROSIS CARE

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Developed by Delaware Media Group in conjunction with the International Organization of MS Nurses (IOMSN)

Publishers: Joseph J. D’Onofrio, Frank M. Marino

Medical Writers: Kaela Hasan, Katherine Wandersee

Art Director: James Ticchio

Hello, and welcome!

This brochure offers a brief overview of the benefits of exercise for people with MS.



As a neurology nurse specialist for over 30 years, I have been privileged to interact with many hundreds of people affected by MS and their loved ones. I often feel that I am learning as much from my patients as they are learning from me! Becoming more informed about the condition and how it affects each individual is one of the most important parts of the relationship between the MS nurse and the patient and family.

This MS Empowerment Series was developed for the International Organization of MS Nurses (IOMSN) to guide the conversation between you and your MS nurse specialist or other healthcare professional. However, the conversation does not stop here. Every person with MS is unique and is affected in different ways. The ideas and resources in this brochure can be used to discuss your own needs and set goals for managing your condition.

I have been inspired by many individuals over the years who have faced and overcome the barriers they encounter. I hope these materials help to inform, guide, and inspire you.

Dorothea “Dottie” Cassidy Pfohl, RN, BS, MSCN

Retired MS Nurse Specialist, Former Clinical Coordinator
University of Pennsylvania Comprehensive MS Center
Philadelphia, PA

STAYING ACTIVE AND HEALTHY WITH MS

For people with multiple sclerosis (MS), regular exercise has been shown to help ease MS symptoms and may help to limit disease progression. But, as anyone facing the challenges of MS knows, keeping fit is often easier said than done. How do you choose your best exercise and get past some of the barriers presented by MS?

How Exercise Can Help to Alleviate Health Problems and Medical Illnesses

There is a growing body of research on how exercise can help people with health conditions such as diabetes, arthritis, even Parkinson's disease. For people with MS, regular exercise has been shown to help with:

- Increased energy/overcoming fatigue
- Muscle strength
- Flexibility and balance
- Stress management
- Cognitive function
- Aerobic and cardiovascular fitness
- Quality of life

Fatigue

At least 80% of people with MS experience some level of fatigue related to the disease. Fatigue may be the reason you decide to stop



"The ideal exercise program for people with MS needs to be individualized. The activity has to be something you are:

- 1) willing to do*
- 2) comfortable doing*
- 3) able to do regularly*

It should be a piece of your life that you enjoy, but not something that becomes a burden."

— SHARON LYNCH, MD
DIVISION CHIEF, NEUROIMMUNOLOGY,
UNIVERSITY OF KANSAS MEDICAL CENTER
DIRECTOR, KU CENTER FOR MULTIPLE SCLEROSIS CARE
AND DIRECTOR, MS ACHIEVEMENT CENTE

exercising—or cause you to take a break and have difficulty getting started again. Studies have shown that periodic exercise may reduce fatigue for people with MS, but stopping an exercise program can actually lead to more fatigue. In one clinical study, 19 people with MS participated in a twice-weekly aquatic exercise program for 12 weeks and noticed significant improvements in fatigue.

How do you break through the fatigue to get back on track? Some tips include:

- Modify the duration of your workout: A workout might be 45 minutes, but 30 minutes may be a better fit for you. If you're in a group class, notify the instructor that you'd like to modify and may need to step out early or take frequent breaks.
- Structure your exercise program so it is challenging for you, but not too strenuous right away. Build up the intensity slowly.

Stress

Normal everyday stressors from work, relationships, and household responsibilities are compounded with the stress of living with a chronic illness like MS. The unpredictability of MS symptoms can be a major source of stress—will this be a good day, or do I need to cancel my plans because of MS symptoms? Research on stress suggests that a certain “good” level of stress keeps us on our toes, but often the needle gets pushed too far into the “red zone” of excess stress (see graphic). Symptoms of stress overload may include mood changes, trouble falling asleep or staying asleep, changes in eating patterns, poor concentration, headaches and abdominal pain. Exercise is a healthy form of stress management, helping you feel more in control of your health and your life. Some of the best stress-reducing exercises—like yoga and tai chi—are well suited to people who have MS.



Cognitive function

Difficulty thinking clearly or focusing on a task is another issue that affects a large number of people with MS. Recent research suggests that exercise may help to boost cognitive performance in people with MS. Physical exercise may help to encourage *neuroplasticity*, or the formation of new nerve cells and nerve connections in the brain. This is one way in which the brain can adapt and overcome impairment by “rewiring” around the damaged areas. Physical exercise benefits cognition the most when it is combined with mental exercises, such as those taught in a cognitive rehabilitation program.

MS Exercise Success Stories

Some professional athletes have been able to continue being successful after a diagnosis of MS. One example is Josh Harding, a goalie for the Minnesota Wild hockey team who was diagnosed with MS in 2012 and went on to play the best season of his career a year later. Harding retired early from the game but stays active as a hockey coach. “I’m not going to sugarcoat it—it was very tough for me,” Harding was

quoted as saying, “Right when I thought that I kind of had [MS] under control, it just seemed like something would kick my legs out from under me again.”

Another inspiring example is that of Cheryl Hile, a marathon runner who has not allowed MS to slow her down. Ten years after her diagnosis she achieved her mission to run 8 marathons on 7 continents in a span of 12 months. Hile, who runs with a custom-made carbon ankle-foot orthotic to provide stability, has completed 30 marathons since her diagnosis in 2006.

While these examples are inspirational and encouraging, every person’s experience with MS and life circumstances are different. This should not discourage you from choosing activities that are right for you. To maintain a regular exercise program and continue to grow with it, this often means choosing activities that:

- Fit your abilities. Focus on what you can do, not on what you think you can’t.
- Work realistically with your schedule.
- Are things you enjoy doing. Try to combine an element of fun, social interaction, and physical benefit.

What Are Good Exercises for People with MS?

Exercises that encourage stretching of your muscles can increase range of motion to decrease pain and discomfort and increase flexibility. Activities that have been studied most in

people with MS include yoga, tai chi, Pilates, and exercises that build muscle strength.

Yoga


Yoga can help relieve MS symptoms such as stiffness, fatigue, and pain. Yoga poses are targeted to benefit your muscles, joints, posture, and core function. Some specialized yoga programs have been developed specifically for people with MS and can be adapted for those with mobility limitations or spasticity. An added advantage is the ability of yoga to help you gain control over stress and anxiety.

Meditation

Meditation could be considered mental exercise—a way of clearing your mind from distracting thoughts. Meditation can help people with MS to improve sleep quality and to decrease fatigue, stress, anxiety, and pain. Meditation pairs well with yoga because the poses train the body for the stillness and focus needed in meditation. There is no one way to meditate, so activities that help you to narrow your focus and relax your body can count as meditation. If you find you have a hard time staying focused, try a guided meditation or a meditation “app” for your phone (see Resources).

Tai chi

Tai chi is an Eastern martial art that combines breathing exercises and slow, focused movements. In tai chi, you learn to shift your weight from one side of the body to the other, which improves balance. Tai chi may improve flex-



"I didn't think I could do Pilates. I talked to an instructor in advance, she suggested some changes I could make, and said I should just try a regular class. In the first class I barely lasted 10 minutes. But some of the other students said they had the same experience at first. That gave me the encouragement I needed to stay with it. A benefit I didn't expect was better bladder control, which I felt I gained by building my core muscles."

— JILL, NEW YORK CITY AREA

ibility, gait, balance, concentration, muscle strength, and overall quality of life. Because it is low intensity, tai chi can be performed at any age or fitness level. If you find the patterns of tai chi difficult to learn, consider Qigong (pronounced chee-gong), which offers many body-healing benefits with a range of shorter exercises.

Pilates

Pilates emphasizes 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, and can be done in the comfort of your own home or in a structured class. Pilates targets flexibility, range of motion, and muscle strength. By strengthening the core, some added benefits can include improved bowel and bladder control.

Strength-building exercises

As we age, it becomes harder to maintain muscle mass. For people with MS, this is an extra challenge due to the effects of MS on strength, balance, spasticity (an involuntary tightening of the muscles), paresthesia (tingling or numbness), and ataxia (uncoordinated movements). If movement is impaired, then sitting more and walking less becomes a vicious cycle that leads to further weakness.

Strength-building exercise may involve use of hand weights, a weight machine, or even your own body weight—a technique used in some forms of Pilates. If you're wondering whether training with weights is right for you, discuss this with your doctor or with a qualified therapist (see Resources).

Aquatic exercise

Exercising in water may help you move in ways you had not thought possible. Buoyancy can make exercises seem easier and encourage muscle relaxation. At the same time, the water's resistance gradually improves muscle strength

and improves balance. Since high heat can be problematic for people with MS, exercising in cooler water might be preferable. (The National Multiple Sclerosis Society recommends water temperatures of 80 to 84 degrees.) You need not be a strong swimmer to perform water exercises, since many activities can be performed in standing depth.

Ai chi is a water-based exercise similar to tai chi. This consists of slow, deep breathing and structured movements. *Ai chi* may improve balance, flexibility, muscle strength, and fatigue in people with physical disabilities.

Professionally Guided Exercises

Expert advice from a rehabilitation specialist or physical therapist (PT) can help you to advance your existing abilities and work around your limitations. It is best to select a professional therapist who has experience with MS, whenever possible. Although this may not be feasible in every geographic area, the International Organization of MS Nurses (IOMSN) can provide local listings of qualified rehab therapists (see Resource Box). A therapist can personalize an exercise program to your own abilities and preferences and can help to monitor MS symptoms such as heat sensitivity, fatigue, and muscle weakness. To get the most out of PT, let the therapist know your personal goals and specific areas where you would like to focus.

People with advanced MS and mobility lim-

itations may want to explore specialized programs. For example, the University of Kansas MS Achievement Center offers a Weekly Wellness Program for people with advanced MS, with rehabilitation services and psychological support in a group setting of 8 to 10 people. The group meets one day a week for five hours, rotating through activities like yoga, music, and cognitive training. Chief neurologist and Program Director Sharon Lynch, MD, says, “I have seen a lot of improvement among participants, in terms of getting from place to place, interacting socially, and being more a part of their care.”

Sticking With Your Goals

It is normal to expect there will be times when exercise is just not realistic, due to factors related to MS, medication side effects, or just “real life” conflicts. Many people find that they drop their exercise program during these times and have trouble restarting. It’s important to pick up from where you are now. You may not have lost all the benefits you had gained. Make a list of your fitness goals, and revise them if needed.

It’s great when exercise can be combined with leisure or social activities that you enjoy. Activities like hiking, dancing, or gardening, can improve your overall health and quality of life. Look into “Meetup” groups in your area that involve walking or hiking, or ask some friends to be regular walking partners.

RESOURCE LIST

Resource	Source/Contact Information
IOMSN LiveWise Program An article on “The Practice of Sport in Multiple Sclerosis” provides a thorough review of the available research on exercise in MS.	www.LivewiseMS.org > Resources Search: Physical activity
Local NMSS Chapter Activities Check your local 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, horseback riding, and adventure trips.	www.nationalmssociety.org > Chapters > Wellness-Programs NMSS: 800-344-4867
IOMSN Stress Reduction Webinar The IOMSN offers an online stress reduction webinar for people with MS that includes tips on yoga, meditation, and other stress-reducing strategies.	www.msperspectives.com > Managing Stress in MS, A Webinar for People with MS
Smartphone Workout Apps <i>SworKit Workouts</i> There are many free apps to help you track and plan your exercise. SworKit is one example: it offers workouts of varying difficulty, focusing on different areas of your body, lasting anywhere from 5 to 60 minutes.	https://sworKit.com App is available for IOS, Android, and Google Play devices.
Smartphone Meditation Apps For help with meditation and some guided meditation suggestions, check out the many available smartphone apps, including the recommended ones here. (Use caution when uploading confidential information into an app.)	Buddhify: Offers a variety of quick meditations to suit your mood \$4.99 Headspace : Helpful guidelines for beginners on learning to meditateFree Calm: 21-day programs to fit your ability levelFree Meditation Timer Pro \$1.99



3 University Plaza Drive, Suite 116
Hackensack, NJ 07601

Tel: (201) 487-1050
Fax: (862) 772-7275

iomsn.org
Email: info@iomsn.org