


MSAA

Winter/Spring 2012

# *The* **MOTIVATOR**

**Bringing Information to People with Multiple Sclerosis**

A photograph of two women sitting on a wooden bench in a gym. They are both smiling and wearing light blue short-sleeved shirts and white towels draped over their shoulders. The woman on the left is wearing dark grey athletic pants, and the woman on the right is wearing white athletic pants. In the background, various gym equipment like treadmills and ellipticals are visible.

*The Benefits of*  
**Physical and  
Social Activity**



# THE BENEFITS OF PHYSICAL AND SOCIAL ACTIVITY

The importance of filling your life with the activities and people you value

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**R**emaining active and engaged in life can be challenging with any chronic condition, including multiple sclerosis (MS). Despite the challenges, living a rewarding life – one that is filled with the activities and people you value – doesn't need to be out of reach. In this article, we'll discuss the benefits of physical and social activity for people living with MS, and provide some strategies for engaging (or re-engaging) in those areas.

## PART I: PHYSICAL ACTIVITY

People with MS may face major challenges when trying to resume physical activities that they enjoyed before their symptoms began. According to the article, “Physical activity and its measurement and determinants in multiple sclerosis” [RW Rotl, *Minerva Med.* 2008 Apr;99(2):157-65], “Overall, there is fairly strong and consistent evidence that individuals with MS are largely inactive compared with non-diseased populations... and the emerging research has highlighted the role of symptoms in explaining inactivity in this population.”

Although remaining active may be more difficult when experiencing symptoms, increasing one’s physical activity has the potential for significant health benefits among individuals with MS. Currently, no clear recommendations are available on the amount of physical activity that is appropriate for people with MS. Guidelines for adults without a chronic condition are 150 minutes of moderate-intensity aerobic activity (such as walking) per week, plus muscle-strengthening activities at least twice per week. The best advice is to talk to your doctor or physical therapist about the amount and type of regular physical activity that is right for you.

You may find many benefits to remaining physically active, both for your body and for your mind. Studies of individuals with MS indicate that exercise results in improved strength, reduced pain, less stress, improved mood, and greater endurance. Regular

exercise can also help prevent other diseases that can impact your life and your health. We know that exercise provides many benefits to your heart and vascular system. It can increase the efficiency of the heart, and decrease the risk of heart disease. Regular physical activity can lower blood pressure and decrease harmful (LDL) cholesterol, while increasing good (HDL) cholesterol. Exercise can also help regulate blood sugar levels and prevent diabetes. In addition, physical activity can help to maintain muscle strength, maintain bone density and reduce the risk of fracture, and regulate breathing.

Another important benefit of exercise for individuals with MS is that it can help you to maintain your current level of physical function, or perhaps even regain some of the function and strength you may have lost. For example, you might be able to strengthen your leg muscles, or improve your level of cardiovascular fitness, enabling you to remain independent and perform activities of daily living that are important to you. These may include basic, everyday activities such as bathing and dressing, taking care of things around the house, and running errands.

Remaining physically active can also improve some of the symptoms of MS. We know from research that people with MS who exercise can decrease pain and increase blood flow to the lower extremities. Exercise can also decrease hospitalizations resulting from some of the effects of MS. Exercise has been shown to improve energy levels and reduce general fatigue – an important issue for many

individuals living with MS. Regular exercise may also help you to maintain your mental sharpness.

We also know that exercise can have a powerful impact on mood. People who are more active are less likely to experience low mood or depression. By the same token, research has shown that increasing your level of physical activity can be an effective way to improve mood. Inactivity might even contribute to the higher rates of depression we see in individuals with MS. One study

found that aerobic exercise was an effective treatment for major depression and was as effective as sertraline (the generic version of Zoloft®, an antidepressant) for treating major depression in older adults. Interestingly, people treated with exercise were significantly less likely to relapse back into a depressive episode as compared to those who only took the sertraline.

Even if you're not struggling with depression, exercise can still have a positive impact on mood and on the overall quality of your life. Physical activity is one of the most effective tools that we know of to relieve stress. Exercise can also help you to feel more in control of your MS symptoms. It can increase your self-confidence and contribute

to a healthier body image. And, depending on what kind of activities you do, exercise can provide great opportunities for social interactions. For example, you could walk regularly with a friend or neighbor, or perhaps find an exercise class designed specifically for people with MS. In many communities, there are MS aquatics programs and adapted yoga programs that are often appropriate for individuals with mobility issues.

Kathy Zackowski, PhD, OTR, MSCS is an



occupational therapist and assistant professor in the Department of Physical Medicine and Rehabilitation, Kennedy Krieger Institute, at Johns Hopkins University School of Medicine in Baltimore,

Maryland. Dr. Zackowski explains, “Individuals with MS can also take regular exercise classes and look for beginner classes. If you feel uncomfortable doing this, talk with the instructor so he or she knows to help you modify exercises or stretches that may be too difficult.”

Any exercise program needs to be appropriate for your capabilities and limitations, and may need to be adjusted as changes occur in your MS symptoms. A physical therapist experienced with the unique and varied symptoms of MS can be



helpful in designing a well-balanced exercise program, along with adjusting it in the future as needed. If you are thinking of starting a new exercise program, you should also consult with your physician to be sure the exercises will be safe for you.

Dr. Zackowski adds, “An occupational therapist can help you to make choices about how to fit in time for exercise and where in your home you can best do your exercises. He or she can also provide tips on how to conserve your energy with your daily tasks, so you have energy left for exercise.”

## ■ TYPES OF PHYSICAL ACTIVITY

Three main categories of physical activity will be reviewed in this article:

- **Stretching and flexibility**
- **Aerobic activity**
- **Strength training**

In general, a warm-up is recommended before engaging in any of these three types of activity. A warm-up just means getting your body moving for five to ten minutes. For example, you can do some light walking or wheeling, swing or punch your arms, roll your shoulders, or lightly tap your toes from side to side. Any slow and controlled movements that start to get your heart rate up will work as a warm-up.

Stretching and flexibility exercises can be done gently at the start of a workout (after you warm up), more deeply at the end of an aerobic or strength-training workout, or alone. Yoga is one example of an extended

stretching or flexibility type of workout. The gentle movements of tai chi may also be a good way to stretch. Although studies about the benefits of stretching are mixed, stretching can help you to improve your flexibility, provided your doctor approves. Better flexibility may improve your performance in physical activities (making basic activities of daily living easier) and decrease your risk of injuries by helping your joints to move through their full range of motion. Stretching also increases blood flow to your muscles.

***Here are some tips to consider when stretching:***

**Don't use stretching as a warm-up exercise.** You may hurt yourself if you stretch cold muscles. Either warm up before you stretch, or stretch after you exercise when your muscles are already warm.

**Focus on major muscle groups.** When you're stretching, focus on your calves, thighs, hips, lower back, neck, and shoulders. You may wish to focus on muscles and joints that are especially stiff from your work or play. Make sure that you stretch both sides of your body; if you stretch your left hamstring, be sure to stretch your right hamstring, too.

**Don't bounce.** Bouncing as you stretch can cause small tears in the muscle, making you less flexible and more prone to pain. Hold each stretch for about 30 seconds, remembering to relax and breathe as you wait for the 30 seconds to go by. Repeat each stretch three or four times.

**If a movement hurts, you've pushed too far.** Expect to feel tension while you're stretching, but not pain. If you feel pain, back off a bit until the pain goes away.

**Keep up with your stretching.** You can achieve the best benefits by stretching at least two to three times per week.

Aerobic exercise is any activity that increases your heart rate. This can include activities such as moderate to fast walking or wheeling, running, dancing, swimming, water aerobics, bicycling or arm cycling — the possibilities are almost endless! When you are doing aerobic exercise, monitoring your heart rate and level of exertion is very important. The three levels of intensity, or “hardness,” of exercise are light, moderate, and vigorous. In general, aiming for at least moderate-intensity exercise offers the best health benefits (again, with your doctor's approval). With moderate-level activity, you will feel as though you are working somewhat hard, but you will also feel that you can keep going for awhile. Your heart may be beating harder and faster than normal, but not extremely fast. Also, your skin may be warmer than normal and could be sweaty as well.

**Strength training** is simply moving weights or using resistance, with the goal of building muscle and bone strength. The three

basic factors in strength training are repetitions (“reps,” or the number of times you perform the move), sets (a certain number of repetitions performed in a row), and weight (the amount you are lifting, usually stated in pounds).

***Here are some tips for any strength-training regimen:***

**Start with lighter weights** until you are comfortable with the moves and your body

positioning. Whether you're sitting or standing, don't strain other parts of your body to complete the move.

**Find a weight that you can lift between 10-15 times without getting too tired.**

If you can perform more than 15 reps easily, the weight is probably too light for you. If you have trouble getting to 10 reps before tiring, try a lighter weight.

**In general, two to three**

**sets** of any given strength-training exercise is suggested, with a short rest in between.

**Don't work the same muscle groups every day.** You can either alternate muscle groups (upper body one day, lower body the next) or take rest days in between strength-training workouts to give your muscles time to recover.

Elastic exercise bands, available from physical therapists or at sporting goods stores, are a nice alternative to hand weights.







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AMPYRA may cause serious side effects including kidney or bladder infections. The most common side effects are urinary tract infection, trouble sleeping (insomnia), dizziness, headache, nausea, weakness, back pain and problems with balance. Tell your doctor if you have any of these side effects that bother you or do not go away.

This is not the full safety information. For more information, please refer to the Medication Guide on the next page. This important safety information is not meant to replace discussions with your doctor.

For more information call toll-free 1-888-881-1918

*You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.*

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Read this Medication Guide before you start taking AMPYRA.

Read this Medication Guide before you start taking AMPYRA and each time you get a refill. There may be new information. This information does not take the place of talking with your doctor about your medical condition or your treatment.

### What is the most important information I should know about AMPYRA?

AMPYRA can cause seizures.

- Your chance of having a seizure is higher if you take too much AMPYRA or if you have kidney problems.
- Do not take AMPYRA if you have ever had a seizure.
- Before taking AMPYRA tell your doctor if you have kidney problems.
- Take AMPYRA exactly as prescribed by your doctor. See “How do I take AMPYRA?”

### Stop taking AMPYRA and call your doctor right away if you have a seizure while taking AMPYRA.

### What is AMPYRA?

AMPYRA is a prescription medicine used to help improve walking in people with multiple sclerosis (MS). This was shown by an increase in walking speed.

It is not known if AMPYRA is safe or effective in children less than 18 years of age.

### Who should not take AMPYRA?

#### Do not take AMPYRA if you:

- have ever had a seizure
- have certain types of kidney problems

### What should I tell my doctor before taking AMPYRA?

#### Before you take AMPYRA, tell your doctor if you:

- have any other medical conditions
- are taking compounded 4-aminopyridine (fampridine, 4-AP)
- are pregnant or plan to become pregnant. It is not known if AMPYRA will harm your unborn baby. You and your doctor will decide if you should take AMPYRA while you are pregnant
- are breast-feeding or plan to breast-feed. It is not known if AMPYRA passes into your breast milk. You and your doctor should decide if you will take AMPYRA or breast-feed. You should not do both.

**Tell your doctor about all the medicines you take**, including prescription and non-prescription medicines, vitamins and herbal supplements. Know the medicines you take.

Keep a list of them and show it to your doctor and pharmacist when you get a new medicine.

### How should I take AMPYRA?

- Take AMPYRA exactly as your doctor tells you to take it. Do not change your dose of AMPYRA.
- Take one tablet of AMPYRA 2 times each day about 12 hours apart. Do not take more than 2 tablets of AMPYRA in a 24-hour period.
- Take AMPYRA tablets whole. Do not break, crush, chew or dissolve AMPYRA tablets before swallowing. If you cannot swallow AMPYRA tablets whole, tell your doctor.
- AMPYRA is released slowly over time. If the tablet is broken, the medicine may be released too fast. This can raise your chance of having a seizure.
- AMPYRA can be taken with or without food.
- If you miss a dose of AMPYRA, do not make up the missed dose. Do not take 2 doses at the same time. Take your next dose at your regular scheduled time.
- If you take too much AMPYRA, call your doctor or go to the nearest hospital emergency room right away.
- Do not take AMPYRA together with other aminopyridine medications, including compounded 4-AP (sometimes called 4-aminopyridine, fampridine)

### What are the possible side effects of AMPYRA?

#### AMPYRA may cause serious side effects, including:

- Kidney or bladder infections
- See “What is the most important information I should know about AMPYRA?”

#### The most common side effects of AMPYRA include:

- urinary tract infection
- trouble sleeping (insomnia)
- dizziness
- headache
- nausea
- weakness
- back pain
- problems with balance
- multiple sclerosis relapse
- burning, tingling or itching of your skin
- irritation in your nose and throat
- constipation
- indigestion
- pain in your throat

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

These are not all the possible side effects of AMPYRA. For more information, ask your doctor or pharmacist.

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

### How should I store AMPYRA?

- Store AMPYRA at 59°F to 86°F (15°C to 30°C).
- Safely throw away AMPYRA that is out of date or no longer needed.

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

### General Information about the safe and effective use of AMPYRA

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use AMPYRA for a condition for which it was not prescribed. Do not give AMPYRA to other people, even if they have the same symptoms that you have. It may harm them.

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

For more information, go to [www.AMPYRA.com](http://www.AMPYRA.com) or call 1-800-367-5109.

### What are the ingredients in AMPYRA?

**Active ingredient:** dalfampridine (previously called fampridine)

**Inactive ingredients:** colloidal silicon dioxide, hydroxypropyl methylcellulose, magnesium stearate, microcrystalline cellulose, polyethylene glycol, and titanium dioxide.

Distributed by: Acorda Therapeutics, Inc.  
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They are inexpensive and easy to store, and come in several different resistance levels (different colors correspond to the degrees of difficulty).

## ■ SAFETY

Safety is a priority for any exercise program. Individuals with MS may need to pay particular attention to body-heat issues. If you are particularly sensitive to heat, you may consider using cooling methods while you exercise, such as a damp cloth, fan, spray bottle, or cooling vest. Heat-sensitive individuals should exercise during the cooler times of the day. People with MS also need to pay close attention to fatigue. If physical activity is making your fatigue worse overall, you may need to slow things down a bit. You will be more likely to stick to an exercise program if you implement it gradually, over a longer time period.

## ■ TAKING ACTION

So, how do you get started on an exercise program? You can find many ways to do this, but research shows that some strategies are better than others:

**Start gradually.** Make a plan for increasing your activity slowly.

**Find activities you enjoy and can do easily.**

Do you love to hike? Maybe swimming is your thing? If so, see if you can participate in these activities. Or, you can try something new! Take a class in something that is of interest and new to you such as Zumba, belly dancing, tai chi, or yoga. For many, just doing more of what you are already doing, such as walking, is a great place to start. You can increase the time and intensity gradually, maybe by 5 percent, and go from there.

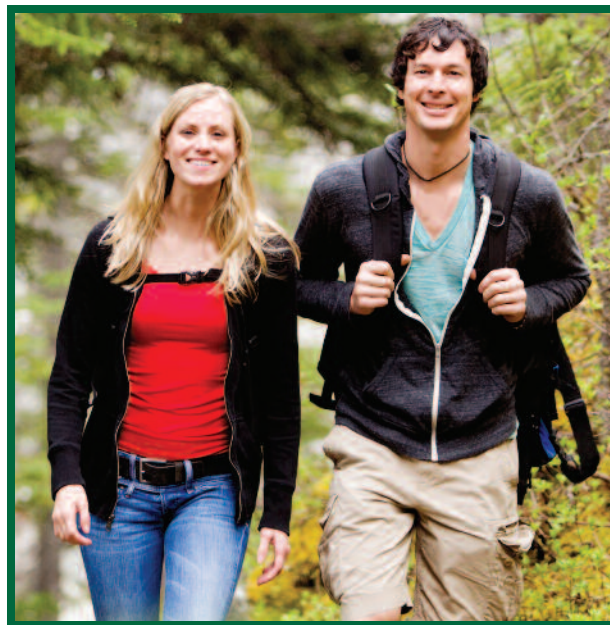
**Find a way to work exercise into your daily or weekly routine,** so you won't have to think about it as much. Consider the time of day that you are the most energetic, and plan to exercise at that time.

**Goal setting is important,** and you can write down or tell someone what you intend to do. The most effective goals

are not simply to say, "I'm going to exercise." Be specific – ideal goals will include what you will do, when, where, how long, and so forth.

**Self-monitoring is also important,** and this can be as simple or as detailed as you would like. Check off the days you meet your goals, such as exercising at least 10 minutes or walking a certain distance. You may want to keep a log of your exercises, weight used, repetitions, and so forth.

**Feedback can be very helpful** to your progress. Look at the self-monitoring data you are keeping. How far are you walking



now versus two weeks ago? How many repetitions now versus when you started? Notice your progress. When you can't meet your goal, identify the barriers and see if you can find ways to safely overcome them. Keep in mind that with MS, you may have certain limitations that you didn't have before, and you need to avoid any type of overexertion – so goals that are too difficult will need to be adjusted to best fit your abilities.

**Positive consequences can provide motivation for**

you to continue to work toward your long-term exercise goals. As you reach new accomplishments, reward yourself! Don't be stingy. If you are moving in a positive direction, even though you might have only completed 50 percent of what you hoped, this merits recognition. Plan the reward ahead of time. Think of healthy ways to treat yourself that are easy to do and fit your budget. Ideas might include: renting a new movie to watch with family or friends, treating yourself to a healthy dessert (such as a



## RESEARCH ON THE BENEFITS OF EXERCISE

According to the article, “Effect of Exercise Training on Depressive Symptoms Among Patients With a Chronic Illness” [MP Herring, et al., *Arch Intern Med.* 2012; 172(2):101-111], lack of exercise and depression are commonly observed in individuals with chronic illness. In this meta-analysis, 90 articles involving studies of more than 10,500 inactive patients were systematically reviewed. Researchers concluded that for individuals with a chronic illness, exercise reduces the symptoms of depression. They also found that individuals who have mild-to-moderate depression and experience improved function from exercise, have the largest reduction in their depressive symptoms.

Another large review of research literature was conducted to determine the relationship between physical activity and cognitive function. Results were reported in the article, “Physical activity for the prevention of cognitive decline” [MD Denkinger, et al., *J Gerontol Geriatr.* 2012; 45:11-16]. Among the “practical conclusions” of this study, researchers found that “Physical activity is beneficial for older adults in primary, secondary, and tertiary prevention of dementia and it is never too late to start.” Researchers also found that moderate-intensity exercise, including brisk walking, for at least 30 minutes per day and five days per week, provided the best results.



fruit smoothie), buying something new to wear while working out, putting fresh-cut flowers in a vase to enjoy and remind you of your success, or simply allowing yourself some extra time to rest and appreciate what you have accomplished.

**Reminders are a quick and easy way to keep exercise on your mind** – and we can all use these types of cues and prompts.

Whether is it a low-tech sticky note on the bathroom mirror, a digital reminder on your smart phone, or a friend who calls you at the time you are due to be out the door — any reminder that works for you can help you to get going and stay on track. Another idea is to consider exercising at the same time each day (you can still vary your activities so some

days you only stretch and other days you are doing cardio or strengthening). By planning to exercise at the same time each day, this becomes easier to remember.

**Exercise with a friend.** Having someone to work out with is a great help to sticking with an exercise program. Walk with a neighbor, find a workout partner, or join a class at your local gym or YMCA/YWCA. This gives you the benefit of both physical and social activity at the same time! (The benefits of social activity appear in Part II of this article.)

### ■ RESOURCES TO HELP YOU

If you need help getting started on an exercise program, many resources are available to help you! First, talk to your

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doctor to make sure exercise will be safe for you. A physical therapist who has experience in working with people with MS may have some great ideas. A local occupational therapist may know of community resources. Look into online resources such as the National Council for Physical Activity and Disability (at [www.ncpad.org](http://www.ncpad.org)) and MS-specific agencies and support groups. Your local YMCA/YWCA or community center may also have good and inexpensive options for increasing your physical (and social!) activity. MSAA has recently launched its new database, *My MS Resource Locator* (at [resources.msassociation.org](http://resources.msassociation.org)), which provides many contacts for a variety of services.

### WHEN EXERCISE BECOMES A CHALLENGE

Kathleen Costello, MS, ANP-BC, MSCN, is a research associate/nurse practitioner at The Johns Hopkins MS Center (part of Johns Hopkins University) in Baltimore, Maryland. She notes, “Many times patients have fatigue levels or mobility issues that cause them to feel that they cannot exercise at all. It is tough to think that exercise can be incorporated in a day when one has barely enough energy to do what is absolutely necessary. In these situations, an evaluation with rehabilitation specialists can be most helpful to design an exercise program with goals that are realistic and attainable. Even when mobility is significantly compromised, exercise is still possible – and can still be quite beneficial.”

MSAA Senior Director of Services Cindy

Richman explains, “When patients experience more weakness or loss of strength, they really need to be evaluated by a physical therapist. The longer someone waits, the more difficult exercise and other activities may become for that individual. Sometimes spasticity is an issue that gets in the way, yet in most instances, spasticity can be managed. Often patients just wait too long or don’t realize their options – and this can be avoided. No one should miss out on the many valuable benefits of exercise and physical activity simply because he or she wasn’t aware of the opportunities available.

“I also want to emphasize that people who have more burden of disease may continue to exercise as well, provided they have their doctor’s approval. Physical and occupational therapists are able to recommend exercises designed specifically for individuals who need to perform activities from a sitting or even a reclining position. Finding a physical or occupational therapist with experience in MS is important, and consulting your neurologist or MS center for a recommendation is a good way to find the right professional. If this is not possible, individuals should ask questions to evaluate the therapist and ensure that he or she has enough experience with MS.”

Readers are also reminded that MSAA’s Multiple Sclerosis Information (MSi) online video and webinar library has two on-demand videos available to view on the topic of exercise. Both may be accessed by going to MSAA’s website at [www.msassociation.org](http://www.msassociation.org) and going to the MSi section.



MSAA's Lending Library also has references available on the topic of exercise and MS. You may view a listing of MSAA's book and DVD collection available for free loan by going to MSAA's website and selecting "programs" and then "Lending Library" (presently in the left-side navigation).

## PART II: SOCIAL SUPPORT

Our social relationships have a powerful influence on our health and well-being. Social relationships are what tie us to the other people around us: our significant other, friends, family, co-workers, neighbors, and community or religious groups. The study of social relationships typically uses the following terms and definitions:

**Social Support:** this looks at what you can gain from social relationships. Social support is considered one of the most important benefits of social relationships.

**Social Network:** this is the web of social relationships that surround a person. Yes, this was a term, long before Facebook came into existence!

**Social Integration:** this refers to the extent of social relationships, including how many or how few one may have.



Social support can take many forms. Here are some of the most important ones.

**Emotional Support:** providing empathy, love, trust, caring, respect, and listening.

**Instrumental or Material Support:** tangible or concrete aid and services that directly assist a person in need. For instance, a person could provide instrumental support by driving someone to a doctor's appointment or helping someone to obtain an assistive device, such as a cane. Providing household goods or financial assistance is another example of this type of support.

**Informational Support:** providing advice, suggestions, and information that a person can use to address problems. An example of this would include a daughter looking for information on depression and MS on the internet, and then passing it along to her mother who has MS.

**Appraisal support:** providing information that is useful for self-evaluation purposes – in other words, constructive feedback, affirmation, and social comparison. This would include having someone you can trust to "tell it like it is," such as when you're blowing something out of proportion or acting unreasonably.

You can't tell by looking at someone whether they have "enough" social support.

Therapists have no objective test, like a blood test, that measures what levels of social support someone has. In order for researchers to gather information on social support, we use standardized questionnaires that are usually completed by the person being studied (this is called self-report), or sometimes questionnaires will also be filled out by the person's significant other or care partner. One of the questionnaires our group at the University of Washington uses is called the Multidimensional Scale for Perceived Social Support (MSPSS). Here are some examples of the types of statements that are used on the MSPSS where someone would rate on a scale how much they agree or disagree:

*There is a special person who is around when I am in need.*

*I get the emotional help and support I need from my family.*

*I can count on my friends when things go wrong.*

*I have a special person who is a real source of comfort to me.*

Scores on a questionnaire like the MSPSS can help us to determine whether an individual has strong social support, or whether he or she may need help expanding his or her social-support resources. To follow is a brief summary of some of the research findings on social support in people with MS.

First, for individuals with MS, social support may increase their ability to cope and adjust to their changing health issues. Just

knowing that you have a community from which you can get help can be empowering. Second, several health benefits were associated with higher levels of perceived social support. These benefits include:

- Lower levels of stress
- Better pain outcomes
- Protective factor against depression
- Better overall quality of life

### ■ WHY DOES SOCIAL SUPPORT MATTER?

Research has identified many good reasons to care about social support, but one of the most important might be the direct impact that social support can have on your health. Several theories have been developed to explain how social support contributes to health in general. One theory is that when you meet the basic human needs for companionship, intimacy, a sense of belonging, and reassurance of one's worth as a person, supportive relationships may enhance wellbeing and health, even if the person is dealing with a lot of stress. Sometimes this is referred to as "buffering," which uses the theory that the more social support we have around us, the more we're able to deal with stressful situations or events in our life (such as the diagnosis or management of a long-term illness). Social support may be particularly important for people living with a chronic condition like MS.

MS can also be stressful for spouses or partners. Significant others of individuals with MS often describe relationship changes that go





## VOLUNTEERS WANTED FOR PHONE STUDIES

The University of Washington is seeking volunteers for two studies. Both are conducted **over the phone** and are open to anyone living in the United States.

### INMOTION STUDY / EXERCISE AND DEPRESSION

**PI: Charles Bombardier, PhD**

This study is for people with SCI (spinal cord injury) or MS who are 45 years of age or older who are feeling down. This study compares two approaches to helping people become more physically active. This study is six months long and compensates up to \$120. The research team can be reached at **(866) 928-2114** or **agerrtc@uw.edu**. You may also visit **<http://agerrtc.washington.edu>**.

### TAKE CHARGE STUDY / SELF MANAGEMENT

**PI: Dawn Ehde, PhD**

This study looks at treatment for pain, fatigue, and depressed mood related to MS. Treatments teach you different ways of managing these problems in hopes of reducing them and their impact on your life. This study is 13 months long and compensates up to \$120. The research team can be reached at **(888) 634-6778** or **msrrtc@uw.edu**. You may also visit **<http://msrrtc.washington.edu>**.

## How to S.E.A.R.C.H.<sup>TM</sup> for the Right MS Therapy for You!



Multiple sclerosis is an ever-changing landscape. With eight treatments available and more on the horizon, how do you decide which is the right MS therapy for you?

Much like a GPS system, MSAA has developed the S.E.A.R.C.H.<sup>TM</sup> tool to help you and your physician navigate through the ever-changing MS landscape and reach your desired destination.

Each letter represents the key areas that should be considered when searching for the most appropriate MS treatment. S.E.A.R.C.H.<sup>TM</sup> stands for **Safety; Effectiveness; Affordability; Risks; Convenience; and Health Outcomes.**

*This program is made possible through unrestricted educational grants from Bayer HealthCare Pharmaceuticals, Biogen Idec, and Teva Neuroscience.*

To learn more about S.E.A.R.C.H.<sup>TM</sup> – including a downloadable patient workbook, treatment chart, resource guide, and a reference card, call **(800) 532-7667** or visit **[www.msassociation.org](http://www.msassociation.org)**.

hand-in-hand with an MS diagnosis. Some significant others (or care partners) report feeling helpless and wishing they could do more, but are often not sure what they can do. Some significant others may be very good at one type of social support, such as instrumental support (tangible aid and services that directly assist a person in need), but aren't sure how to provide a deeper emotional support. Couples counseling may be an option during this time to ensure your relationship stays strong, that communication stays open, and to give both people the best tools to support one another. Support groups for spouses and care partners of people living with MS are also available and some may find these to be very helpful.

Dr. Zackowski notes, "Some occupational therapists are trained to provide strategies for enhancing your, and your partner's, social support network. Community rehabilitation centers are a good place to look for these types of supportive tools."

### MAINTAINING SOCIAL SUPPORT DURING CRITICAL PERIODS

MS can be characterized as a series of transitions. During these critical periods, the demands and stressors associated with MS increase. At times, critical periods are directly associated with MS, such as when a person is initially diagnosed. At other times, these periods reflect changes in social roles. For example, the need to retire prematurely. During these critical periods, social support is vital.

**Initial Diagnosis.** When first diagnosed, individuals with MS often tell us about a

coping or adjustment period that takes place and is stressful. People living with MS (as well as their significant other) often describe feelings of anger around the time of their initial diagnosis. Feeling this way could have a negative impact on your relationship with your significant other, family, and friends. Working through and understanding these feelings – while eventually moving past them – are important. Of course, individuals still need to recognize that MS will continue to present certain challenges even after the anger is gone. Consulting a psychologist is one way to get some extra help during a time like this.

Other people report that participation in MS support groups can be very helpful during the diagnosis period. This allows people to connect with others who have similar struggles and experiences, as well as being able to learn more about MS from people who have lived with the disease longer. However, other people have reported that some MS support groups were not as helpful — if they didn't have people who were similar to them. For instance, a man with MS may benefit more from talking with other men; a mother with MS who has young children may prefer talking with other moms. Be sure to ask about the support groups you are considering and see if you can locate one that will best fit your needs.

Ms. Richman cautions, "Newly diagnosed individuals need to be careful about getting involved in a group too quickly. When individuals with MS do not have a good social-support system, seeking some transitional counseling first can be very

helpful as they go through an initial period of adjustment. Once they gain back some control, they may consider a group, but only if the group mirrors themselves. Participation in a group where attendees may be older and have much more burden of disease can make the situation worse for a newly diagnosed or younger patient. Failing to succeed in a group, along with the pressure that participation may bring, could be viewed as another failure – and I never want anyone to think that he or she cannot relate to and interact comfortably with his or her peers.”

**When symptoms are invisible.** Early in the course of the disease, when many symptoms of MS are “invisible,” some people discuss resistance to telling people (family, friends, etc.) about their diagnosis of MS. Unfortunately, this tactic can backfire and isolate the person even further. Keeping MS a secret could cut off a whole network of support, limit the types of support available to you, and may unevenly burden your significant other as they become your only confidant.

People with MS also report high levels of stress during a relapse, when their MS worsens, or during other periods of change (such as financial or healthcare-related), due

to their MS. They face a wide range of secondary conditions including pain, fatigue, depression, trouble sleeping, and trouble thinking or memory problems. A person living with MS may not be dealing with just one secondary condition, but is often juggling several, if not all of these problems. These secondary conditions may not only increase stress, but could also impact a person’s social relationships. For instance, a person who is feeling depressed may not be interested in

“hanging out” with other people; or a person struggling with fatigue may not have the energy to participate in the activities that he or she used to do with friends.

**When needs increase.** As time goes by after a diagnosis of MS, people in the social

network of a person living with MS may take on a new role: that of a care partner. Care partners accept the responsibility of taking care of someone who is aging, has a disability, or has a chronic condition. This is sometimes called “caregiving.” Responsibilities of care partners could include managing medications, helping with doctors’ appointments (scheduling, asking doctors questions, etc.), helping to dress or bathe the person, transportation, as well as taking care of household chores, meals, and bills.





In surveys we have conducted at the MSRRTC (MS Rehabilitation Research & Training Center), people have reported using their social networks far more often than paid care assistants to meet their caring needs — further evidence of how important a strong social network can be in the lives of individuals with MS. Research indicates that men and women approach the role of a care partner differently. Women are more likely to use their entire social network for support, whereas men with MS tend to rely primarily on their significant other. Men are less likely to ask for outside help and are reluctant to express their feelings about the situation.

The transition to a care partner relationship may be slow or fast, depending on what type of MS you have. People living with MS and their significant others have reported higher levels of stress during transitions that

are more unexpected or that happen quickly. Being prepared and planning for the future may ease the stress during these transitions. Also, having a social network of people who are willing and able to help out as needed may reduce the stress and take the burden off of the primary care partner. The MSRRTC has published a book, *The MS Workbook: Living Fully with Multiple Sclerosis*, which has a valuable chapter on care partner relationships. Some communities have caregiving classes that instruct people on how to be a good care partner. Check with your local Red Cross, senior services office, or local MS center to see if these classes are available in your area.

### ■ TAKING ACTION

Several options are available if you feel that your social support resources need strengthening. Here are some ideas:

## ***Physical Activities for Individuals with MS***

**By Maryann B. Hunsberger**

People with MS know how tricky it can be to get enough physical exercise. Yet, opportunities exist. Wellness centers at local hospitals, the local Y, colleges, high school adult evening classes, and senior centers are all good places to call to find mild exercise programs that can be tolerated by individuals with MS.

National organizations sometimes have local classes geared toward people with disabilities. Some programs to choose from are:

The Arthritis Foundation has classes suitable

for many people with MS. Their website, **[arthritis.org](http://arthritis.org)**, has a “programs” section with various adapted exercise programs, including:

***Walk with Ease:*** An exercise program designed to reduce pain and improve overall health for people who can stand for 10 minutes without increased pain.

***Tai Chi:*** A program aimed at reducing pain and improving mental and physical wellbeing. The program uses gentle routines that are suitable for every fitness level.

***Aquatic Program:*** This warm-water\* non-weight-bearing exercise program is designed to reduce pain and improve overall health and is suitable for every fitness level. (\*Please note

### Private counseling with a psychologist.

Sometimes it's difficult to determine where to draw the line in a social relationship. Perhaps your current network is not qualified to help you with the particular problem you're dealing with. Counseling and problem-solving with a psychologist or therapist may help you to determine what assistance you need and who might provide the best support. A good counselor can also help you with coping and stress management. The good news is that more and more health insurance plans are now covering coun-



seling (at least partially). If you are experiencing difficulties with pain, fatigue, depression, sleep, or memory, ask your doctor for a referral to a rehabilitation psychologist. Check with your health insurance to find out what they will cover.

### Couples counseling with a psychologist.

Intimate relationships change in the face of a chronic condition and some couples may benefit from talking to a licensed psychologist or counselor. Some therapists may specialize in couples counseling, so be sure to ask if that is their specialty.

*that warm water is usually contraindicated in MS and is recommended to be below 85° F; water temperature should be discussed prior to starting an aquatic program.)*

**Exercise Program:** A low-impact program that helps reduce pain and decrease stiffness. The gentle range-of-motion exercises are suitable for every fitness level.

Individuals seeking a Certified Inclusive Fitness Trainer can search the American College of Sports Medicine's Pro Finder link at **certification.acsm.org**. These trainers lead people with disabilities in safe, adapted exercise.

Individuals with MS who can't keep up with their old treadmill routine might like underwater

treadmills. Because these treadmills are on a pool floor, at least half of the body is submerged in water, removing weight from joints and allowing for a pain-free cardiovascular workout. Call local physical therapy organizations and rehabilitation hospitals to find these treadmills.

Hippotherapy uses horseback riding to increase trunk strength, balance, and endurance. Participants often enjoy spending time with the horses, while the experience of sitting up high and feeling the horse walk effortlessly across the ground can also have a freeing effect on the rider. Visit **americanhippotherapyassociation.org** for more information. ■

**Support groups for individuals with MS.** Some people find that talking with other people who have similar experiences and understand what it's like to live with MS is particularly helpful. Support groups are offered through a variety of organizations and could be in-person, over-the-phone, or online. Some groups are led by a peer (someone else with MS), whereas others are led by a professional facilitator.

**Support groups for care partners (or significant others) of people with MS.** These types of groups give your significant other a

chance to connect with other people who are going through similar experiences that they are.



**Caregiving Training Classes.** The American Red Cross offers information and local classes on caregiving. To learn more, visit [www.redcross.org](http://www.redcross.org) and type “family caregiving” in the search window. This will bring you to a

list of options, which includes a detailed publication (titled *Family Caregiving*) that may be downloaded and viewed or purchased. Local caregiving classes are

## ***Social Activities for Meeting New People***

**By Maryann B. Hunsberger**

How can someone with MS get out and meet new people? In many cases, they can accomplish this in the same way that people without MS meet people – by participating in activities that focus on things they enjoy. It's easier to find things to talk about with people who share the same interests. People who enjoy reading can discuss their favorite books at a book club. Gardening enthusiasts can get new tips and make new friends at a gardening club. Additionally, book stores may offer

occasional book signings, while large garden/home improvement centers often hold various instructional classes.

Taking – or teaching – adult evening classes at local high schools and community centers can be a great way to find like-minded people. Whether teaching techniques of painting or learning more about playing Bridge, these classes provide an outlet for encountering others who enjoy the same hobbies. Community colleges also have many classes available, from noncredit floral arranging classes to for-credit international language classes. Can you really meet new people in your local college's French class? Mais oui! (Roughly translated... “Of course!”)



provided by the Red Cross as well. Nine one-hour classes are offered on topics such as legal and financial issues, home safety, personal care, and healthy eating. Another good resource for caregiving classes is the National Family Caregivers Association (NFCA). You may learn more by visiting their website at [www.thefamilycaregiver.org](http://www.thefamilycaregiver.org). The NFCA offers educational workshops to instruct family caregivers on how to communicate more effectively with healthcare professionals. They recommend that anyone interested visit their website to see if a workshop is scheduled in his or her community.

**Get Involved.** Some people prefer to find support that is unrelated to MS, such as becoming more involved with a local civic organization (local parks, local government, community center, humane society, etc.).

Check out what volunteer opportunities are available in your area.

**Group Exercise.** This can be as simple as meeting your family or friends for a Saturday walk in the park (if able, walking in general is a great form of exercise for everyone), or if you're more ambitious, joining a running group (these are often associated with running stores). Group exercise, such as Zumba, yoga classes, or spin classes (using stationary bikes at the gym) can bring a sense of camaraderie as you accomplish a challenge together as a group. Some people report that exercising with a group also adds a sense of accountability to continue week to week (in contrast to individual exercise, where it's sometimes too easy to give yourself a day off!). Depending on the magnitude of your symptoms, your local gym or specialized gyms

*(continued on page 28)*

Volunteering is another way to find friends. Rather than stewing about the abused animals you care about – donate your time at an animal shelter, feeding and showing love to neglected animals. You'll meet people who love animals in the process. If you're concerned about homeless people, take time to serve meals at the nearest homeless shelter. Reading to individuals who are visually impaired is another important and rewarding volunteer opportunity. You'll meet other volunteers while providing help, no matter which cause you choose.

And if thinking about volunteering... you can combine your desire to volunteer with your need for exercise and social activity, all while

raising money to help individuals with MS! MSAA's Swim for MS program allows participants to have an individual or group swim event – anywhere and anytime – to help raise funds for the programs at MSAA. Please visit [msassociation.org/swimforms](http://msassociation.org/swimforms) for more information.

People with MS who use wheelchairs sometimes find it hard to meet others when so much of the world is inaccessible. Some individuals who meet others during social activities at accessible houses of worship find that newer worship buildings are generally more wheelchair-friendly. The community living section at Wheelchairnet

*(continued on page 28)*



GILENYA for relapsing forms of multiple

POSSIBLE

## GILENYA. Proven to significantly reduce the

**GILENYA reduced the number of relapses by 52% in a 1-year study versus IM interferon beta-1a. In fact, 83% of people taking GILENYA remained relapse-free versus 70% taking IM interferon beta-1a.**

**GILENYA was also proven effective in a separate 2-year study versus placebo.**

### Indication

GILENYA is a prescription medicine used to treat relapsing forms of multiple sclerosis (MS) in adults. GILENYA can decrease the number of MS flare-ups (relapses). GILENYA does not cure MS, but it can help slow down the physical problems that MS causes.

### Important Safety Information

GILENYA may cause serious side effects such as:

- Slow heart rate, especially about 6 hours after your first dose. If your heart rate slows down, you might feel dizzy or tired, or be aware of a slow or irregular heartbeat. Your doctor will watch you for the first 6 hours after your first dose for any serious side effects. If you experience slow heart rate, it will usually return to normal within 1 month. Call your doctor if at any time you have dizziness, tiredness, or a slow or irregular heartbeat. If you stop taking GILENYA for 2 weeks or more, you will need to repeat this observation.
- Increased risk of serious infections. GILENYA lowers the number of white blood cells (lymphocytes) in your blood. This will usually go back to normal within 2 months of stopping GILENYA. Your doctor may do a blood test before you start GILENYA. Increased risk of infection was seen with doses higher than the approved dose (0.5 mg). Two patients died who took higher-dose GILENYA (1.25 mg) combined with high-dose steroids. Call your doctor right away if you have fever, tiredness, body aches, chills, nausea, or vomiting.
- Macular edema, a vision problem, can cause some of the same vision symptoms as an MS attack (optic neuritis), or no symptoms. Macular edema usually starts in the first 3 to 4 months after starting GILENYA. Your doctor should test your vision before you start GILENYA; 3 to 4 months after you start GILENYA; and any time you notice vision changes. Vision problems may continue after macular edema has gone away. Your risk of macular edema may be higher if you have diabetes or have had an inflammation of your eye (uveitis). Call your doctor right away if you have blurriness, shadows, or a blind spot in the center of your vision; sensitivity to light; or unusually colored vision.
- Breathing problems. Some patients have shortness of breath. Call your doctor right away if you have trouble breathing.
- Liver problems. Your doctor should do blood tests to check your liver before you start GILENYA. Call your doctor right away if you have nausea, vomiting, stomach pain, loss of

**GILENYA™** *go*  
program™

**1-800-GILENYA or visit [gilenya.com](http://gilenya.com)**



sclerosis (MS). Discover your

# BILITIES

number of relapses in the first once-daily\* pill.

appetite, tiredness, dark urine, or if your skin or the whites of your eyes turn yellow.

- Increases in blood pressure (BP). BP should be monitored during treatment.

GILENYA may harm your unborn baby. Talk to your doctor if you are pregnant or planning to become pregnant. Women who can become pregnant should use effective birth control while on GILENYA, and for at least 2 months after stopping. If you become pregnant while taking GILENYA, or within 2 months after stopping, tell your doctor right away. Women who take GILENYA should not breast-feed, as it is not known if GILENYA passes into breast milk. A pregnancy registry is available for women who become pregnant during GILENYA treatment. Call 1-877-598-7237 for more information.

Tell your doctor about all your medical conditions, including if you had or now have an irregular or abnormal heartbeat; a heart rate less than 55 beats a minute; heart problems; a history of fainting; a fever or infection, or if you are unable to fight infections; eye problems; diabetes; breathing or liver problems; or high blood pressure. Also tell your doctor if you have chicken pox or have received the vaccine for chicken pox. Your doctor may do a test for the chicken pox virus, and you may need to get the vaccine for chicken pox and wait 1 month before starting GILENYA.

Tell your doctor about all the medicines you take,

including medicines for heart problems or high blood pressure; medicines that could increase your chance of infections, such as medicines to treat cancer or control your immune system; or ketoconazole (an antifungal) by mouth. If taken with GILENYA, serious side effects may occur. You should not get certain vaccines while taking GILENYA, and for at least 2 months after stopping.

The most common side effects with GILENYA were headache, flu, diarrhea, back pain, abnormal liver tests, and cough.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.

**Freedom from injections is finally an option. Ask your doctor if GILENYA is right for you.**



*\*GILENYA can result in a slow heart rate when first taken. Your first dose will be given in a doctor's office or clinic, where you will be watched for 6 hours. If you stop taking GILENYA for 2 weeks or more, you will need to repeat this observation.*

**Please see Brief Summary of Important Product Information on next pages.**

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**MEDICATION GUIDE**  
**GILENYA™ (je-LEN-yah)**  
**(fingolimod)**  
**capsules**

Read this Medication Guide before you start using GILENYA and each time you get a refill. There may be new information. This information does not take the place of talking with your doctor about your medical condition or your treatment.

**What is the most important information I should know about GILENYA?**

GILENYA may cause serious side effects, including:

**1. Slow Heart Rate (bradycardia or bradyarrhythmia) when you start taking GILENYA.** GILENYA can cause your heart rate to slow down, especially after you take the first dose. Your heart rate will usually slow down the most about 6 hours after you take your first dose of GILENYA. You might feel dizzy or tired or be aware of a slow or irregular heartbeat if your heart rate slows down. Usually, if you experience these types of symptoms due to the slowing down of your heart rate, they will occur during the first 6 hours after the first dose. Your doctor will watch you for the first 6 hours after you take the first dose to see if you have any serious side effects. Your slow heart rate will usually return to normal within 1 month after you start taking GILENYA.

Call your doctor if at any time you have:

- dizziness
- tiredness
- a slow or irregular heartbeat

**2. Infections.** GILENYA can increase your risk of serious infections. GILENYA lowers the number of white blood cells (lymphocytes) in your blood. This will usually go back to normal within 2 months of stopping treatment. Your doctor may do a blood test before you start taking GILENYA. Call your doctor right away if you have any of these symptoms of an infection:

- fever
- tiredness
- body aches
- chills
- nausea
- vomiting

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

Call your doctor right away if you have any of the following:

- blurriness or shadows in the center of your vision
- a blind spot in the center of your vision
- sensitivity to light
- unusually colored (tinted) vision

**What is GILENYA?**

GILENYA is a prescription medicine used to treat relapsing forms of multiple sclerosis (MS) in adults. GILENYA can decrease the number of MS flare-ups (relapses). GILENYA does not cure MS, but it can help slow down the physical problems that MS causes.

It is not known if GILENYA is safe and effective in children under age 18.

**What should I tell my doctor before taking GILENYA?**

**Before you take GILENYA, tell your doctor about all your medical conditions, including if you had or now have:**

- an irregular or abnormal heartbeat (arrhythmia)
- a heart rate less than 55 beats a minute
- heart problems
- a history of fainting (syncope)
- a fever or infection, or you are unable to fight infections. Tell your doctor if you have had chicken pox or have received the vaccine for chicken pox. Your doctor may do a blood test for chicken pox virus. You may need to get the vaccine for chicken pox and then wait 1 month before you start taking GILENYA.
- eye problems, especially an inflammation of the eye called uveitis
- diabetes
- breathing problems
- liver problems
- high blood pressure
- Are pregnant or plan to become pregnant. GILENYA may harm your unborn baby. Talk to your doctor if you are pregnant or are planning to become pregnant.
  - Tell your doctor right away if you become pregnant while taking GILENYA or if you become pregnant within 2 months after you stop taking GILENYA.
  - If you are a female who can become pregnant, you should use effective birth control during your treatment with GILENYA and for at least 2 months after you stop taking GILENYA.

**Pregnancy Registry:** There is a registry for women who become pregnant during treatment with GILENYA. If you become pregnant while taking GILENYA, talk to your doctor about registering with the GILENYA Pregnancy Registry. The purpose of this registry is to collect information about your health and your baby's health.

For more information, you can call the GILENYA Pregnancy Registry at 1-877-598-7237.

- Are breastfeeding or plan to breastfeed. It is not known if GILENYA passes into your breast milk. You and your doctor should decide if you will take GILENYA or breastfeed. You should not do both.

**Tell your doctor about all the medicines you take,** including prescription and non-prescription medicines, vitamins, and herbal supplements.

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

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

Especially tell your doctor if you take:

- Medicines for heart problems or high blood pressure
- Vaccines. Tell your doctor if you have been vaccinated within 1 month before you start taking GILENYA. You should not get certain vaccines while you take GILENYA and for at least 2 months after you stop taking GILENYA. If you take certain vaccines, you may get the infection the vaccine should have prevented. Vaccines may not work as well when given during GILENYA treatment.

- Medicines that could raise your chance of getting infections, such as medicines to treat cancer or to control your immune system.
- ketoconazole (an antifungal drug) by mouth

Ask your doctor or pharmacist for a list of these medicines if you are not sure.

#### How should I take GILENYA?

- Your first dose of GILENYA will be given in a doctor's office or clinic, where you will be observed for 6 hours after your first dose of GILENYA.
- Take GILENYA exactly as your doctor tells you to take it.
- Take GILENYA 1 time each day.
- Take GILENYA with or without food.
- Do not stop taking GILENYA without talking with your doctor first.
- If you start GILENYA again after stopping for 2 weeks or more, you will start taking GILENYA again in your doctor's office or clinic.

#### What are possible side effects of GILENYA?

GILENYA can cause serious side effects.

#### See "What is the most important information I should know about GILENYA?"

Serious side effects include:

- **Breathing Problems.** Some people who take GILENYA have shortness of breath. Call your doctor right away if you have trouble breathing.
- **Liver problems.** GILENYA may cause liver problems. Your doctor should do blood tests to check your liver before you start taking GILENYA. Call your doctor right away if you have any of the following symptoms of liver problems:
  - nausea
  - vomiting
  - stomach pain
  - loss of appetite
  - tiredness
  - your skin or the whites of your eyes turn yellow
  - dark urine

The most common side effects of GILENYA include:

- headache
- flu
- diarrhea
- back pain
- abnormal liver tests
- cough

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

These are not all of the possible side effects of GILENYA. For more information, ask your doctor or pharmacist. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-332-1088.

#### How do I store GILENYA?

- Store GILENYA in the original blister pack in a dry place.
- Store GILENYA at room temperature between 59°F to 86°F (15°C to 30°C).
- Keep GILENYA and all medicines out of the reach of children.

#### General information about GILENYA

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use GILENYA for a condition for which it was not prescribed. Do not give GILENYA to other people, even if they have the same symptoms you have. It may harm them.

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

For more information, go to [www.pharma.US.Novartis.com](http://www.pharma.US.Novartis.com) or call 1-888-669-6682.

#### What are the ingredients in GILENYA?

**Active ingredient:** fingolimod

**Inactive ingredients:** gelatin, magnesium stearate, mannitol, titanium dioxide, yellow iron oxide.

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

GILENYA is a trademark of Novartis AG.

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*(continued from page 23)*

may be interested in providing a personal trainer who may have some experience with the effects of MS.

Ms. Richman notes, “When starting out with a new counselor or therapist, you need to make sure that he or she is right for you. You should ask what this professional knows about chronic illness; ask about his or her credentials, as well as his or her connection to MS. Once you have met with the counselor or therapist, ask yourself if you felt comfortable talking with the individual and why. Having a good fit with your therapist will greatly assist in getting the most benefit from your sessions.

“With regard to group exercise, if an

individual with MS cannot do the same things as his or her spouse, friend, family member or child, he or she has options to exercise in a parallel way. For example, if a friend or family member is running on the treadmill, someone with MS could be alongside him or her on a stationary bike – allowing them to exercise together. Another idea is to swim together, where the natural buoyancy of water enables a patient to enjoy greater mobility. Driving a scooter as another person walks alongside is another example of how to stay active together. These types of parallel activities may encourage people to look for creative ways to make exercise work, while spending more social time with others.”

### ***Social Activities for Meeting New People***

*(continued from page 23)*

**(wheelchairnet.org)** has links regarding accessible worship.

Some people meet friends at exercise classes for people with disabilities. The Arthritis Foundation (**arthritis.org**) stresses that their adapted exercise classes are held in an environment that encourages social interaction.

Centers for Independent Living in every state provide support groups for people with disabilities where friendships can form. Find your local center at **ilru.org**. These centers also provide information and referral to other disability-related organizations with opportunities for socialization.

Travel agencies specializing in wheelchair-accessible vacations can allow wheelchair

users to see the world while making friends, both on cruises and on land tours.

According to Accessible Journeys (**disabilitytravel.com**), some important accommodations to seek from accessible travel agencies are meet-and-greet services at airports and train stations, accessible van rentals, and fully accessible hotels. The book, *101 Accessible Vacations: Travel Ideas for Wheelers and Slow Walkers* by Candy B. Harrington, can be an ideal starting point for those seeking accessible vacations.

Many people with disabilities choose to meet other disabled individuals through online groups and message boards. These can provide socialization to people who have difficulty getting out of the house. ■



## IN CLOSING

Dr. Zackowski concludes, “The most important thing to get across is that people with all disability levels can benefit from increased activity, but it needs to be done thoughtfully. In my experience, patients are very careful about which physician they choose for their medical needs (i.e., a physician with training in MS), but they are not as careful about whom they pick for their physical and occupational therapists (i.e., do the therapists have experience with MS and do they trust their judgment?).

After getting a physician’s agreement that exercise is safe, each person should see a physical therapist to provide specific recommendations. It might be nice to talk a bit about the physical therapist’s qualifications for doing this type of work (i.e., are they trained in the neurology of MS?). I also think that occupational therapy should be included in one’s exercise plans. Occupational therapists play a major role in providing



energy-conservation training, teaching activity modifications, and providing resources for equipment to allow for increased activity within one’s home environment... just to name a few of the ways in which they can help.”

MSAA Chief Medical Officer Dr. Jack Burks adds, “This article integrates

theoretical, scientific, and practical components to support the value of physical and social wellbeing, as people with MS learn to cope with and adapt to their MS. The lessons to be learned and implemented are important for everyone in the MS community, both with or without MS.

“The principles presented are informative, providing ‘words to live by’ as we all strive to increase our quality of life. Everyone has his or her own ‘style’ as to what works best. There is no ‘one size fits all’ in how we approach physical and social activities. However, many points in this article are applicable to all of us.” ■

## ABOUT THE AUTHORS

Samantha Artherholt, PhD is a research counselor and Aimee Verrall, MPH is a researcher at the University of Washington in Seattle, Washington. They work across two center grants called Rehabilitation Research & Training Centers (RRTCs). One RRTC focuses on multiple sclerosis and the other looks at aging with a physical disability. The RRTCs conduct a variety of research including surveys and randomized controlled trials.