

Winter 2016

# MS Perspectives™

Volume 9, Issue 2

Practical Insights on  
Multiple Sclerosis



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Published in partnership with:



**IOMSN**

The International Organization of  
Multiple Sclerosis Nurses



This publication is supported  
by educational grants from Sanofi  
Genzyme, Teva Pharmaceuticals, and  
Genentech.

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Tracy Walker has received honoraria for serving as a consultant and speaker for Acorda Pharmaceuticals, Biogen Idec, EMD Serono/Pfizer, Novartis, Questcor, and Teva Neuroscience.

## Publishing Information

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66 South Maple Avenue

Ridgewood, NJ 07450

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Website: [www.delmedgroup.com](http://www.delmedgroup.com)

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# Your Journey to..... WELLNESS

By Tracy Walker, F-NPC

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Everywhere you look these days you see the word “wellness.” In fact, an entire industry of products, services, and even tourism has developed promising to give us wellness. It is hard to believe that not too long ago the word was rarely used, especially in the healthcare arena. Recently, while researching the history of wellness, Anna Berry, PT, DPT, my colleague at Shepherd Center, came across an old episode of the TV show “60 Minutes” that

aired in 1979, during which reporter Dan Rather described wellness as “a word you don’t hear every day.”

Thankfully today, not only has the word “wellness” become part of our everyday conversation, it has also become an important focus in medicine.

*“Health is a state of body. Wellness is a state of being.”*

— J. Stanford

## *The True Meaning of Wellness*

What does wellness really mean? Early definitions of wellness focused mainly on physical health and the absence of disease. If you had a chronic illness such as multiple sclerosis (MS), wellness was considered out of reach. But physical health is not the end all and be all to wellness.

Over the past 30 years, the concept of wellness has evolved into a much more active and holistic concept of living one’s best life—despite





illness. The National MS Society says wellness is a “dynamic state of physical, emotional, spiritual, and social wellbeing that can be achieved even in the presence of a chronic illness or disability.” And the National Wellness Institute defines wellness as “an active process through which people become aware of, and make choices toward, a more successful existence.”

The common thread in both of these definitions is action. Wellness requires action—whether that action is learning, moving your body, connecting to others, or taking the time to be still and reflective. Wellness is a way of living and thinking, and a perspective on life. It’s a journey—not a destination. That journey can seem overwhelming if you focus on how many miles you need to travel or the wrong turn a few miles back. The key to success is taking it one step at a time and setting clear, realistic goals.

### ***Models of Wellness***

Many different models of wellness have been developed over the years. Most of these models encompass the

body, feelings/emotions, the mind, social connections, spirituality, and work (your job, schooling, or volunteering). Pursuing wellness involves balancing all of these dimensions and recognizing the impact that each area can have on all of the other aspects of your life.

This article will focus on physical wellness. In our forthcoming issues, we will explore the other areas of emotional, intellectual, social, spiritual, and vocational wellness.

### ***Physical Wellness Assessment***

We’ll start with assessing your physical health, related to both your overall health and your MS. Ask yourself:

- Do I know important health numbers, like my cholesterol, weight, blood pressure, and blood sugar levels?
- Do I get annual physical exams?
- Do I avoid using tobacco products?
- Do I get enough sleep?
- Do I have an established exercise routine?
- Do I know where I can go for physical therapy?



## Connections



## Spirituality



## Employment

- Do I use cooling equipment to prevent overheating?
- Do I know how to conserve my energy?

As you answer these questions, you'll begin to formulate a picture of your current state of physical health and where you need to concentrate your efforts to be healthier in relation to your whole body as well as to your MS.

### *Strategies for Improving Your Physical Wellness*

Once you've assessed your current health, it's time to start making some goals (see the next article for advice on that) and following the tips below:

1. Manage your MS—don't let it manage you. Start disease-modifying therapy early and stay on treatment. If you encounter obstacles, speak with

- your provider about other options among the 10-plus drugs that are now available to treat relapsing MS.
2. Eat a healthy diet. Even though research does not suggest that any one diet is best for everyone with MS, it clearly shows that eating well matters for overall health and well-being. So eat your fruits and vegetables in a rainbow of colors and pass on foods high in saturated fats and sodium.

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# BOOK A “HEALTHIFICATION” VISIT!

If you have a lot of questions about nutrition, exercise, dietary supplements, your general health or other health conditions and how they impact your MS, it’s time to book a “healthification visit” with a health professional such as an MS nurse or health coach. The idea, according to Mary Kay Fink, ACNS-BC, an advanced practice nurse at The MS Center of Saint Louis of Missouri who coined the term “healthification,” is to give patients one-on-one time to talk with a health professional about health and wellness concerns that don’t often get addressed during regular visits.

“The one-hour-long visit is really just a regular office visit during which we talk about what’s important to managing overall health—getting preventive care such as mammograms and Pap tests, managing high blood pressure and other comorbidities, and regularly seeing primary care providers,” Fink says. “We then talk about how these things can affect your MS-related health.” Prior to the visit, Fink asks patients to fill out a questionnaire about their general health and lifestyle habits, and to list their three top priorities for the visit, as well as topics on which they’d like more information. During the visit, she helps patients identify three realistic goals and detail what they want to accomplish, how they are going to do it, how they are going to measure success, and who they will turn to for help in achieving their goals.

“We want people to be aware that every decision you make about your overall health will enhance your MS wellness,” she says.

## Your MS Health Visit Goals

**Use this form to create your own goals to share with your MS nurse, a health coach, or other provider.**

Based on today’s visit I would like to establish the following goals:

1. I will \_\_\_\_\_ by \_\_\_\_\_ as measured by \_\_\_\_\_.
2. I will \_\_\_\_\_ by \_\_\_\_\_ as measured by \_\_\_\_\_.
3. I will \_\_\_\_\_ by \_\_\_\_\_ as measured by \_\_\_\_\_.

What steps do I need to take to meet these goals?

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

Who can help/support me? \_\_\_\_\_  
I will meet with \_\_\_\_\_ on \_\_\_\_\_  
to review progress on these goals.

*Information courtesy of Mary Kay Fink, ACNS-BC*

(Continued from page 5)

3. Don't smoke. Several studies have now shown clearly that people who smoke have a much greater risk of MS progression, as well as many other serious negative health effects such as cancer and respiratory disease.
4. Get enough sleep. Most people need at least 8 to 10 hours of rest a day. If you can't sleep or you don't feel rested after sleeping, talk to your provider about sleep strategies and medications.
5. Be sure you have a primary care provider who can help you stay up to date on general health maintenance, such as yearly physicals and screening exams. Research shows that diseases that commonly occur with MS, such as diabetes, cardiovascular disease, and high blood pressure, can have negative effects on MS symptoms if they are not managed well.
6. Join a wellness program or a gym. If you can't make it to the gym, do an exercise video (you can find many free ones on MS websites).
7. If you have rehabilitation needs or you want to become more active but aren't sure how or where to start, ask your provider to refer you to a physical or occupational therapist or an exercise physiologist for an evaluation. These professionals can assess your current exercise capacity and develop a customized program

to help you develop more endurance and get stronger.

8. Limit "screen time." When you do watch TV or surf the Internet, set a time limit and do something physical during every commercial break (arm cycles, fist punches, sit-to-stand maneuvers, or dancing in place).
9. Identify one action you can take this week to improve your physical wellness, from scheduling your yearly physical to trying kale or another "exotic" super-green or taking a walk after supper.



# 4 Essential Tips

## FOR Setting Practical Goals

It's easy to set wellness goals, but it's not so easy to achieve them. We all want to have better health, and we may set goals to lose weight, exercise more, and see our primary care doctors regularly. At first, everything goes well. But typically things fall apart quickly—unless you learn how to craft practical goals that you can achieve over the short term that can lead to bigger and better goals. Here's how:

**Tip# 1: Make the process fun and personal.** You'll be more successful at moving toward your goal if it's synched to something you enjoy and find interesting to do, says Heidi Grant Halvorson, PhD, author of *Succeed: How We Can Reach Our Goals*. In addition, goals that are chosen for personal reasons—because you're hoping to improve your health, for instance—are better motivators. Goals that are chosen to gain outside approval

are less likely to succeed. "You're not going to engage in them fully," she says, "and you're likely to get discouraged quickly and stop doing them sooner rather than later."

**Strategy:** Ask yourself what you can do to make your goal more fun to pursue. For example, if you want to get in better shape but hate the gym, think about activities you do find enjoyable: Short walks on the beach with your dog? Yoga or tai chi classes? A walk after dinner with

your family? Next, add an incentive to strengthen your resolve. Maybe hire a personal trainer to obligate you to work out and to customize an exercise routine, or treat yourself to a weekly post-workout massage.

**Tip# 2: Accept failure as a sign you need to retweak your goal.** Setbacks are part of the process of moving forward. Rather than labeling yourself a failure when your efforts to





reach a goal fall apart, chalk it up to experience and move on. “Berating yourself is counterproductive,” says Kristin Neff, PhD, of the University of Texas (UT) at Austin and author of *Self-Compassion: Stop Beating Yourself Up and Leave Insecurity Behind*. In a study she conducted of UT students and how they coped with failure, she found that students who were self-compassionate were more likely to set a new or revised goal than those who were self-critical. “Being self-critical makes you feel depressed, leads to procrastination and a fear of failure, and makes you believe in yourself less,” she says. “The fact is, it’s human to mess up once in a while.”

**Strategy:** “Be really specific when setting your goal so you have a clear idea of what success looks like,” advises Dr. Grant Halvorson. So, instead of saying “I want to lose some weight,” say “I want to lose 10 lbs. by April 1<sup>st</sup> by eating 1,500 calories a day.” Then, focus on the steps you’re going to take to be successful, including how you’re going to cope with meals out, peer pressure to over-indulge, and food cravings.

**Tip#3: Build your self-control muscle by planning ahead.** Most people think you have willpower or you don’t, and that’s why you succeed or fail at a goal like losing weight. Not true, says Dr. Grant Halvorson. “Self-control is



very much like a muscle. It can vary in strength—not only from person to person but from moment to moment depending on what you’re doing.” The more decisions you have to make and the longer the decision-making process goes on, the more willpower it uses up and the more likely you are to make poor decisions.

**Strategy:** Increase your self-control by making your thinking process

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# MMS RESEARCH UPDATE

By Aliza Ben-Zacharia, DrNP

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**M**S research has been on the rise in the last few decades and new treatments and approaches have been developed for relapsing and progressive MS. At the recent meeting of the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS), held in London in September 2016, promising clinical trial results were announced for several potential MS drugs. There were also, as always in science, some disappointments, such as use of the antidepressant fluoxetine (Prozac®), and the “Anti-LINGO-1” drug opicinumab, neither of which showed effectiveness in stalling progressive MS.

Here are highlights of a few of the most exciting reports:

## *Siponimod for SPMS*

Siponimod, a sphingosine 1-phosphate (SIP) receptor modulator that is in the same class of drugs as fingolimod (Gilenya®), is an oral medication that reduces the number of lymphocytes (immune cells) circulating in your blood. In the EXPAND study reported at ECTRIMS,

siponimod’s safety and effectiveness were tested in secondary-progressive MS (SPMS), for which there are currently no approved therapies. The results were positive, and the drug reduced the risk that disability would progress in people with SPMS by 21% at 3 months and 26% at 6 months compared to a placebo.

## *Lipoic Acid for SPMS*

Lipoic acid is an inexpensive oral antioxidant that may produce anti-inflammatory effects in people with MS. In one small, randomized, controlled clinical trial presented at ECTRIMS, the goal of which was to evaluate the effect of lipoic acid on brain volume in SPMS, there was a trend for a benefit. However, there were also some adverse effects, such as protein in the urine, kidney failure, and gastrointestinal symptoms.





A larger study will be needed to further evaluate the safety and effectiveness of this supplement.

## ***Comparison of DMTs***

One presented trial compared alemtuzumab (Lemtrada®) to other potent disease-modifying therapies (DMTs), including natalizumab (Tysabri®), fingolimod (Gilenya®), and interferon beta-1a (Rebif®), over 5 years in people with relapsing MS. Alemtuzumab was shown to be superior to interferon beta-1a in reducing relapse activity and disability progression in patients with highly active MS. It was also superior to fingolimod in suppressing relapse activity. It was comparable to natalizumab for decreasing relapse activity and disability progression, but natalizumab tended to halt disability progression earlier than alemtuzumab.

## ***A “Hot Topics” Debate: Induction Versus Escalation Therapy***

There was a lot of discussion at theECTRIMS meeting about research looking at what’s called induction therapy versus escalation therapy. These two approaches to treatment both involve using Food and Drug Administration-approved medications



for MS, but in a different order. Escalation therapy is a common approach using the lower-risk DMTs with good efficacy such as glatiramer acetate (Copaxone®) and the beta interferons (Avonex®, Betaseron®, Extavia®, and Rebif®) for early disease and moving to higher-risk/more-effective drugs that suppress immune-system activity such as natalizumab (Tysabri®) and alemtuzumab (Lemtrada®) typically when MS worsens. Induction therapy flips that order, starting with the higher-risk immunosuppressive drugs earlier, followed by the lower-risk DMTs.

Preliminary research suggests that induction therapy might be beneficial for a select group of people with early, aggressive relapsing-remitting MS (RRMS) who have a high burden of MRI lesions, multiple



relapses with poor recovery in the first year after diagnosis, or other signs that predict a poor prognosis. In contrast, it is hypothesized that patients with milder and less-aggressive disease might benefit from escalation therapy starting with the more-established DMTs. Clinicians might choose to use one or the other approach based on their medical opinion and experience, and in consultation with patients with MS and their preferences and values.

These are early observations, however: More randomized, controlled

trials comparing medications to address induction versus escalation therapies in patients with different courses of MS are needed.

## ***Pregnancy Risks with DMTs***

Several studies investigated the risk of pregnancy loss or birth defects in women using certain DMTs while carrying a baby. In general, the results were reassuring in this regard for glatiramer acetate (Copaxone®), fingolimod (Gilenya®), and dimethyl fumarate (Tecfidera®).

## **4 Essential Tips** (Continued from page 9)

automatic. If you want to eat less, for instance, decide in advance how you'll handle problem scenarios, from encountering donuts in the break room to fries at the diner.

**Tip#4: Be realistically optimistic.** Your expectations play a huge role in your success or failure, says Dr. Grant Halvorson. "If you expect the road to achieving your goal will be smooth, you're likely to give up way too soon at the first sign of a roadblock. But if you expect the road to be difficult—you'll make mistakes, you'll feel lost or confused at times—you'll be mentally prepared for the journey ahead."

**Strategy:** Make a list of positive aspects of achieving your goal, as well as the obstacles you'll encounter. "By contrasting the things you have to gain with the obstacles standing in your way, you should have a better sense of how likely you are to succeed, and how committed you are to that success," says Dr. Grant Halvorson.





## Support Programs for MS Disease-modifying Therapies (DMTs)

### **Aubagio,® Genzyme Corporation:**

[www.aubagio.com](http://www.aubagio.com), 855-MSONE2ONE (855-676-6326)

### **Avonex,® Biogen:**

[www.avonex.com/en\\_us/home/above-ms-program/join-biogen-support.html](http://www.avonex.com/en_us/home/above-ms-program/join-biogen-support.html), 800-456-2255

### **Betaseron,® Bayer HealthCare:**

[www.betaseron.com/home](http://www.betaseron.com/home), 800-788-1467

### **Copaxone,® Teva Neuroscience:**

<http://copaxone.com/AboutSharedSolutions.aspx>, 800-887-8100

### **Extavia,® Novartis:**

[www.extavia.com/info/PatientSupport/Patient-support-program.jsp](http://www.extavia.com/info/PatientSupport/Patient-support-program.jsp), 866-398-2842

### **Gilenya,® Novartis:**

[www.gilenya.com/c/go-program](http://www.gilenya.com/c/go-program), 800-GILENYA (800-445-3692)

### **Glatopa,™ Sandoz:**

[www.glatopa.com/glatopa\\_care/](http://www.glatopa.com/glatopa_care/), 855-452-8672

### **Lemtrada,™ Genzyme:**

[www.lemtrada.com/](http://www.lemtrada.com/), 855-MSONE2ONE (855-676-6326)

### **Plegridy,™ Biogen:**

[www.plegridy.com](http://www.plegridy.com), 800-456-2255

### **Rebif,® EMD Serono:**

[www.mslifelines.com](http://www.mslifelines.com), 877-447-3243

### **Tecfidera,® Biogen:**

[www.tecfidera.com/support/ms-support-services.html](http://www.tecfidera.com/support/ms-support-services.html), 800-456-2255

### **Tysabri,® Biogen:**

[www.tysabri.com/en\\_us/home/join-biogen-support/join-biogen-support.html](http://www.tysabri.com/en_us/home/join-biogen-support/join-biogen-support.html), 800-456-2255

### **Zinbryta,™ Biogen and Abbie:**

[www.zinbryta.com](http://www.zinbryta.com)

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

### **Can Do Multiple Sclerosis**

[www.msando.org](http://www.msando.org)

### **MS Views & News**

[www.msviewsandnews.org](http://www.msviewsandnews.org)

### **MS World**

[www.msworld.org](http://www.msworld.org)

### **Multiple Sclerosis Association of America**

<http://mymsaa.org/>, 800-532-7667

### **Multiple Sclerosis International Federation**

[www.msif.org](http://www.msif.org)

### **Multiple Sclerosis Foundation**

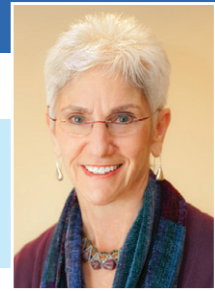
[www.msfocus.org](http://www.msfocus.org), 888-MSFOCUS (888-673-6287)

### **National Multiple Sclerosis Society**

[www.nationalmssociety.org](http://www.nationalmssociety.org), 800-344-4867



# Ask the Clinician



**Q.** I'm told it's important to connect with other people with MS, but how do I build a strong support network?

**A.** MS is a challenging disease for individuals and families, but you don't have to deal with it alone. Creating an extended support network is a way to thrive, to stay engaged with the world, and to avoid the isolation that can come with a chronic illness. In short, building a strong support network provides the instrumental help you may need to function on a day-to-day basis, and it also provides the emotional support that everyone needs to get along in life.

Here are three tips on how to build your network:

**1. Link up with advocacy organizations.**

(See the list of MS resources on page 13 for contact information.) These groups can provide information about the disease, offer support during times of crisis, and give you referrals to resources in your community. At the National Multiple Sclerosis Society (NMSS, [www.nationalmssociety.org](http://www.nationalmssociety.org)), for instance, any person affected by MS—a patient, caregiver, spouse, or other family member—can call 1-800-FIGHT-MS and speak to a highly trained MS navigator for support and referrals. You can also go to the website

[www.MSConnection.org](http://www.MSConnection.org), part of the NMSS, to join online support groups for people with shared interests and common challenges (such as living well despite MS, parenting with a chronic illness, and being a care partner), post comments and questions, or catch up with blogs. Through the website, you can also find a peer support volunteer with whom you can communicate privately via email. And of course, there are scores of NMSS offices around the United States where you can interact in person with other people with MS and participate in educational and recreational activities.

Another support organization is Can Do Multiple Sclerosis ([www.mscondo.org](http://www.mscondo.org)), which is well known for working both with people affected by MS as well as their support partners. This group offers free educational and experiential programs in Colorado, where it is based, and at other sites around the country that allow you to interact with Can Do's clinical consultants (including







myself). The two-day “Take Charge®” program, for instance, is a weekend retreat where participants and support partners attend presentations and workshops and participate in group activities to learn more about MS and how it affects the person with the disease and their families. Alternatively, the one-day “JUMPSTART®” program is held in communities from coast to coast and actively explores health, wellness, and lifestyle empowerment approaches for people with MS and their partners. There is also a webinar series, created in collaboration with the NMSS, which you can access monthly on the Can Do MS website.

**2. Build a medical support team,** including MS experts such as a neurologist and MS nurse, as well as primary care and preventive medicine professionals, physical and occupational therapists, and mental health professionals. Some people may be lucky enough to find their healthcare providers all in one building or area, such as at an MS comprehensive care center, while others who live in rural areas may have to do more legwork to put their team together. Remember to call 1-800-FIGHT-MS for referrals to local providers. Once you’ve established your team, be prepared to seek out new specialists as your needs change



over time, or if you don’t feel you’re able to work collaboratively with a provider on your team.

As a psychologist, I strongly recommend developing an ongoing relationship with a mental health professional who knows about MS. This person can act as a coach and accompany you on your MS journey. It’s very helpful to have someone you can talk with should you begin to experience mood changes, as well as at major transition points, such as if you have to adjust to a new disability or wish to start a family.

**3. Learn to talk with family and friends about your MS.** One of the biggest challenges people encounter when they are diagnosed with MS is teaching others about the disease—how different it is from one person to another and from day to day for any one person—and about when they need help and when they don’t. This requires that you learn to communicate clearly, which doesn’t always come naturally. You may think that others don’t want to or aren’t supporting you, when it just may be that they don’t know what to do or how to help. You have to teach them what to do for you, just as you’ve learned what to do for yourself.

— Rosalind Kalb, PhD  
Program Consultant, Can Do Multiple Sclerosis  
Vice President of Health Care Information and Resources, National Multiple Sclerosis Society  
New York, NY



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