

Accelerated Cure Project for MS

August
2017



*Accelerating research towards a
cure for multiple sclerosis*

Dear Friends,

Managing MS is an ongoing process. It is generally agreed that many of the discouraging symptoms of MS may not be sufficiently relieved by its conventional treatments. This newsletter focuses on treatments that, while beneficial for many, are considered outside of orthodox medicine.

Our first article discusses some of the alternative therapies that many people with MS turn to for relief of symptoms, such as pain, fatigue and depression. In the second article, Dr. Farren Briggs discusses the benefits of exercise for physical and mental health.

Our partner spotlight this month is Can Do MS. Their motivational programs open up possibilities of a fuller life for people with MS and their families.

Don't miss our interview with Freda Spectra Warrington, in which Freda tells us about her family's walk with MS and her first book series, "Listen to the Light".

We appreciate your support and hope that you are enjoying these last days of summer.

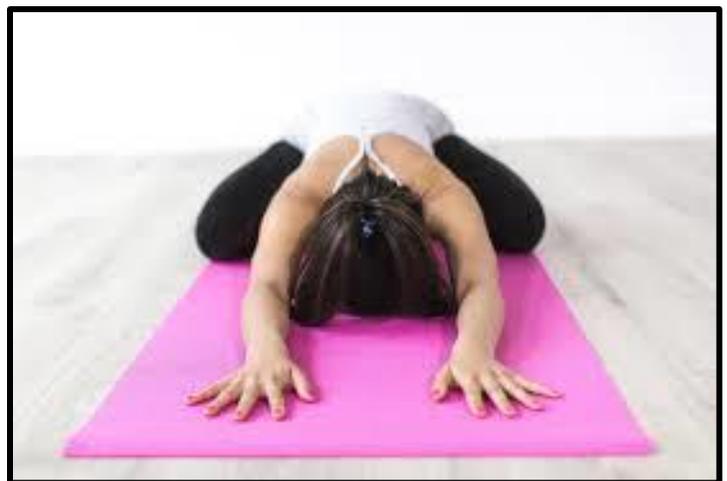
The Accelerated Cure Project Team

Alternative Medicine – Is it right for you?

A variety of medications are used to treat multiple sclerosis (MS). Sometimes people with MS turn to other treatments to manage their symptoms and increase their quality of life, most often in combination with their prescribed MS treatments.

[Acupuncture](#) is an age-old healing practice of traditional Chinese medicine in which thin needles are placed at specific points on the body. It's primarily used to relieve pain but also has been used to treat other symptoms. The goal of acupuncture is to release the flow of the body's vital energy or "chi" by stimulating points along energy pathways. This is thought to release natural painkillers, and may boost blood flow and change brain activity. Acupuncture needles are very thin, and most people feel no pain or very little pain when they are inserted. Some people report relief of symptoms like pain, muscle spasms, or bladder control problems, however there is no scientific evidence that it works for people with MS. If you decide that acupuncture is right for you, it's important to see a licensed acupuncturist for your treatments. If you are afraid of needles, you may be able to get much of the same benefit from [acupressure](#). Acupressure involves pressing or massaging the acupuncture points to stimulate energy pathways.

In addition to being important to general health and well-being, some types of exercise can be helpful in managing MS symptoms by lowering stress, helping you relax, and increasing your energy, balance and flexibility. Exercise doesn't have to be rigorous to provide benefits. You don't need to belong to a gym or health club. Many exercises can be done at home and modified if they cannot be done in the 'traditional' way (for example, using a hand cycle instead of stationary bicycle, or exercising while sitting down). Any physical activity done on a regular basis (walking, gardening, or even cooking) has been found to reduce stress and improve physical and mental health. Practicing [yoga](#) can help increase core strength and flexibility, while providing relaxing benefits that are helpful for releasing tension. Yoga combines poses with proper



breathing and thought processes to bring peace to the mind, body and spirit. Every pose can be simplified and can be practiced in a variety of positions for those who may be less able. Most yoga studios offer different styles and levels of classes. [Tai Chi](#) is a martial art that combines slow, deliberate movements, meditation and breathing exercises. This can help restore your energy, balance, and alignment. Tai Chi is said to be gentler than yoga. Many of the positions can be done while sitting. As with any fitness program, check with your doctor before you start. An exercise program needs to fit your capabilities and limitations and may need to be adjusted as changes occur in MS symptoms. Be aware that any exercise can elevate the body's core temperature and temporarily aggravate MS symptoms. Periods of exercise should be carefully timed to avoid the hotter periods of the day and prevent excessive fatigue. Some find that exercising in water is especially beneficial. Water helps people with MS move in ways that they may not be able to on land, and keeps them cool while they are exercising.

Relaxation and stress management are important for managing MS symptoms. Everyone manages stress differently. In general, keeping a positive attitude and minimizing stress producers in your life can help you feel better. Sharing your thoughts and feelings can help relieve stress. Joining [iConquerMS™](#) or the [iConquerMS Smart Patients community](#) are ways to participate in groundbreaking research and connect with others to share feelings and opinions; and, perhaps, help you see stressors in a new light. Managing expectations is important in managing stress. MS is changeable and flexibility in expectations is the key to keeping stress levels low. Many people with MS get regular [massage therapy](#) to help them relax and reduce stress. Others find that [meditation](#) greatly decreases the stress in their lives. Meditation is often incorporated into the practice of yoga, as the physical poses of yoga prepare the body to sit in stillness for mediation. There is no single, correct way to meditate. Walking can be a form of meditation. Knitting, gardening, observing nature or any other activity that causes you to narrow your focus can be meditative. The benefits of meditation may address many of the issues faced by people diagnosed with MS without the use of medication.

Although there's no special "MS diet," what you eat can make a difference in how you feel. MS specialists recommend that people with MS follow the same high fiber, low fat [diet](#) that is recommended for all adults. Different diets have been proposed as treatments (for example, the [Swank diet](#)), or even cures, for MS symptoms. Most have not been studied adequately, and the few that have been studied have produced mixed results. Several

herbal remedies and vitamins are said to be beneficial in managing MS symptoms. It is well known that [vitamin D](#) promotes calcium absorption for strong bones. However, recent research also suggests Vitamin D may play a role in [myelin repair](#) and [protecting the brain](#) in people at risk for developing MS. [Biotin](#), sometimes referred to as Vitamin B7 or Vitamin H, is one of the B complex vitamins. Biotin is found in many foods, such as brewer's yeast, nuts, egg yolks, Swiss chard, and liver. [Several studies](#) on the use of high levels of biotin as a treatment for people with progressive MS have shown positive results. It is important to note that these are preliminary studies and that not every person who took part in the studies saw the same degree of improvement. More research is needed to determine who might benefit from this approach. There is some evidence that taking [Evening Primrose oil](#) (linoleic acid) may slightly improve MS symptoms. Linoleic acid can be found in sunflower seeds and safflower oil.

There is much controversy surrounding the therapeutic use of [marijuana](#) for MS. Some people with MS say that smoking or ingesting marijuana brings relief of many MS symptoms. However, scientists aren't clear on how it works and who should use it. Marijuana is a complex substance that may contain many different components affecting the body. Production of marijuana for medical use is not standardized or regulated, therefore the effects of different batches of marijuana may not be the same. While many people are using marijuana, the FDA still hasn't approved it as a treatment because there haven't been enough studies to prove that it's safe and effective. This research is necessary to understand whether or not the benefits of marijuana use outweigh its many side effects. If you live in a state where medical marijuana is legal, it's important to consult with your doctor about the use of marijuana in your particular situation.

Many people with MS turn to [music therapy](#) for management of their MS symptoms. Not only does music have calming effects, but it can also improve memory and lessen depression. Doing repeated movements to a rhythmic beat can improve coordination and concentration; and, in turn, also affect endurance and improve one's walking gait. Verbal communication may also benefit from music therapy. Words that are hard to verbalize can sometimes be easily communicated when put to music.

Pet therapy is a form of treatment where animals are used to improve a patient's condition. The most common animal used is a dog, but others including cats, horses, dolphins and farm animals are also used. [Studies have shown](#) that the use of animals can calm anxiety, lower blood pressure, reduce pain, and change mood. The [Therapy Dogs International](#) and the Delta Society's [Pet Partner's](#) program both focus on pet therapy. It is common for therapy animals to visit health care facilities and libraries. [Studies have also shown](#) that having a pet at home can reduce multiple sclerosis symptoms, if the patient is able to take care of the pet or has caregivers that can help with the pet.



The treatments your physician prescribes for you are the ones that have been evaluated in controlled clinical trials or accepted by the MS medical community as safe and effective therapies. In contrast, most alternative treatments have undergone very little (if any) scientific study to evaluate their safety and effectiveness. Some may be completely safe for a person with MS while others may actually pose significant risks. Some may provide benefit for a person with MS while others offer no benefit at all. When considering alternative treatments, it's important to find out what the treatment is, what's involved and how it works. It's also important to ask about side effects, risks, effectiveness and cost. Talk with your doctor before you start any new therapy. Together you can decide what will help you feel your best (whether the benefit of the therapy outweighs the risks). It's important to keep your physician informed about what you take (or what is done) and any changes you experience, this will allow your doctor to alert you to possible side effects or drug interactions.

Talking to others who have used the therapy may also help with this decision. Your doctor may also be able to give you information on other patients who may have tried the same therapy that you are considering. It's also important to research the provider's background. Find out about their credentials and how long they've been offering the treatment. Be sure that the provider is willing to work with your doctor and be fully informed about the total cost of the treatment (most are not covered by insurance). Be wary of outrageous claims and "secret" formulas (make sure all ingredients are listed).

New surveys on diet, wellness, and complimentary approaches to REAL MS will be added to [iConquerMS](#) at the end of August. If you haven't already done so, please



[join](#) and share your information about your treatment and experiences. The research enabled by this information is the key to better understanding the safety and effectiveness of many of these alternative therapies.

Physical fitness and Multiple Sclerosis: To exercise or not to exercise?

By Farren Briggs PhD, ScM



Earlier this week I was moderating a group discussion among first year medical students on a hypothetical medical case where a physician prescribed his diabetic patient to lose fifty pounds and exercise regularly in order to manage their chronic condition. The students initially thought nothing of this statement, but as we revisited the *prescription*, they realized the prescription was non-specific without an actionable plan to encourage adherence and compliance of the diabetic patient to the *treatment*. The physician did not give any practical advice on nutrition, healthier food substitutes, best practices for weight loss, or where to begin with exercise – thus, the hypothetical patient would have been left uninformed and unfortunately be stuck with the same old habits. The students and I spoke about various approaches to improving the *prescription*, for example [motivational interviewing](#) by the physician as a means of identifying the patient's values and desires, and using that information to facilitate and encourage personal behavior change. I am the first to admit I have always been biased to the positive possibilities of exercise on physical and mental health, but for several years I saw exercise as a luxury, competing with the limited time I had to spend on *more* important things. Fortunately, I had an academic coach use motivational interviewing to help me realize exercising was a cornerstone of my daily life, and by exercising, I was more productive and effective when I applied myself to other activities. This month there were several publications, not on motivational interviewing, but on physical activity – suggesting exercise improves various outcomes in MS.

The first publication, by Claflin *et al*, was a systematic review of 9 exercise studies published between 2001 and 2016¹, which included 260 persons with MS (PwMS). These studies were individually small, often exploratory (thus lacking replication), with varying study designs and health outcomes measured. However, when the 9 studies were reviewed collectively, they demonstrated exercise improved health outcomes for PwMS, particularly mobility and muscular strength.

The second article was a randomized controlled trial of 62 PwMS with substantial mobility disability (EDSS>4 [significant disability but able to walk without aid or rest for 500m] and <6 [requires a walking aid to walk 100m]), conducted by Sandroff *et al*². PwMS were assigned to one of two 6-month programs: 1) multimodal exercise training (a combination of aerobic, resistance and balance exercises – this was the *intervention*), or 2) stretching-and-toning (the *placebo/control* activity). The two groups of PwMS did not differ at baseline, and multiple aspects of mobility, gait, physical fitness, and cognitive processing speed were measured. After 6 months, the participants in the multimodal exercise group significantly improve their walking speed (distance covered in 6 minutes), peak power (a measure of physical fitness), and scores on a cognitive processing speed test (3' Paced Auditory Serial Addition Test; PASAT), compared to the stretching-and-toning group. Overall, this study provide preliminary evidence suggesting multimodal exercise training might be a useful rehabilitative approach to improve various outcomes in PwMS who already have substantial disability, and adds support to Claflin's systematic review.



The last study that caught my attention was by Souza *et al*, and was not a study of humans, but of mice with experimental autoimmune encephalomyelitis (EAE), an animal model of MS³. The mice were randomly distributed to 4 groups: naïve, EAE, EAE plus strength training (ST), and EAE plus endurance training (ET). How does one strength train a mouse? Well the animals were first familiarized to climbing a ladder from bottom to top. Then a small load was secured to the base of each animal's tail, and the animals were then trained to climb the ladder for 30 minutes in a series of repetitions and breaks. The training last 5 days a week, for 4 weeks. The load was

¹ <https://www.ncbi.nlm.nih.gov/pubmed/28768821>

² <https://www.ncbi.nlm.nih.gov/pubmed/28732757>

³ <https://www.ncbi.nlm.nih.gov/pubmed/27447807>

also increased over time. The mice in the ET group were habituated to a treadmill at 10m/min for 10min/day – the *running* program was increased in speed and duration to 13-17 m/mins for 5 days/week for 4 weeks also. The researchers evaluated many outcomes, and ST and ET had numerous positive outcomes. The most striking and relatable are the observations for the accrual of disability after initiation of EAE (**Figure 1**). Both the ST and ET groups had lower clinical scores (less severe disease), and the ET group had a delayed onset of symptoms (~day 15), compared to the EAE group that did not exercise. The study also demonstrated ST and ET reduced oxidative stress, the production of inflammatory cytokines, and permeability of the blood-brain-barrier – these results are fascinating.

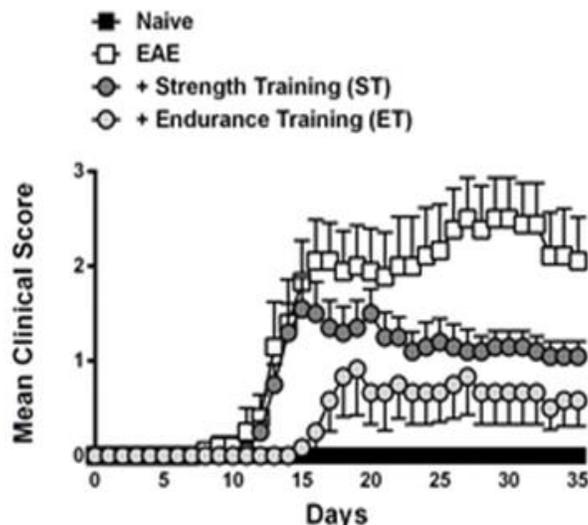


Figure 1: ST and ET inhibited the development of EAE. (Adapted from Souza, P.S., Gonçalves, E.D., Pedroso, G.S. et al. Mol Neurobiol (2017) 54: 4723)



Overall, these 3 publications continue to emphasize that exercise has a positive impact on various outcomes in PwMS. The U.S. Department of Health and Human Services recommends for adults of any age, that some physical activity is better than none – and health benefits can be gained from as little as 60

minutes of aerobic activity per week (there is no need to “feel the burn”)⁴. PwMS should have honest conversations with their neurologists and primary care physicians about possible fitness programs and seek recommendations for a physical therapist. In the least, one can benefit from being informed, and should the opportunity arise to start exercising, I encourage one to first identify one’s motives (Why exercise? How will my family and I benefit if I exercised?); then develop a plan that is simple and manageable with **actionable** goals (i.e. walking 5 more minutes a week); and lastly, try something new, such as aquatic Tai Chi with a friend.

⁴ <https://www.nhlbi.nih.gov/health/health-topics/topics/phys/recommend>

Can Do MS – committed to thriving with MS

Can Do MS is a national nonprofit organization based in Avon, Colorado whose mission is to provide every person affected by multiple sclerosis (MS) with the knowledge and tools they need to feel a sense of control over MS and have the best quality of life possible. They do this through a positive, “can do” philosophy coupled with a variety of lifestyle empowerment programs for people with MS and their families.



Can Do MS programs focus on a variety of lifestyle topics, such as exercise, nutrition, work, home, communication, relationships and the spiritual aspects of living with MS. They also include clinical topics, such as cognitive health, symptom management, rehabilitation, mobility, bladder/sexual function and psychological support. Spouses, family members and/or friends are strongly encouraged to participate in all programs. Can Do MS works collaboratively with MS care providers and organizations around the US and Canada to ensure that their programs are made available to as many people living with MS as possible.

Can Do MS programs are of varying lengths, the longest of which is their [CAN DO](#) program. This is a four-day program that provides comprehensive assessments and education about MS. Participants have the opportunity to develop a personalized lifestyle plan through seminars, workshops, support groups and goal setting. This program also provides guidance on how to seek out the necessary resources for its participants to live the fullest life possible. Participants receive personalized attention from and have the opportunity to have one-on-one discussions with medical professionals.

The [TAKE CHARGE](#) Program is a weekend retreat for people with MS and their families. This program provides MS education through lectures. Participants also have the opportunity to interact with experts in the field of MS, professional staff and fellow participants during workshops and group activities so that each participant has a personalized experience and can obtain the maximum benefit for their individual situation.

[JUMPSTART](#) is a free, one-day educational program during which participants interact and explore the wide range of lifestyle and clinical topics mentioned above. JUMPSTART programs are offered across the country. Visit the [Can Do MS website](#) for more

information, and to find upcoming JUMPSTART programs in your area. Can Do MS also offers a free [webinar series](#) that can be accessed from the convenience of home. Can Do MS consultants and MS experts participate in these webinars and serve as a resource for any questions that may arise. For more information, and to register for upcoming webinars, please click [here](#).

[Live Fully, Live Well](#) is a pilot program from the National MS Society and Can Do MS that is offered in the classroom setting. Participants have the opportunity to interact, connect and share with others. The goal of Live Fully, Live Well is for every participant to develop a wellness plan so that they can optimize their quality of life with MS. Visit the [National MS Society website](#) to find local programs.

Can Do MS also offers [adaptive ski programs](#) to people living with MS, which are in honor of their founder, Jimmie Heuga. Jimmie was an Olympic ski racing medalist that was diagnosed with MS during the height of his skiing career and went on to be an advocate of exercise and fitness to combat the disease. These unique programs, which are part of the [Ski for MS](#) event series, are offered at mountains across the country and provide opportunities to improve fitness and develop friendships.

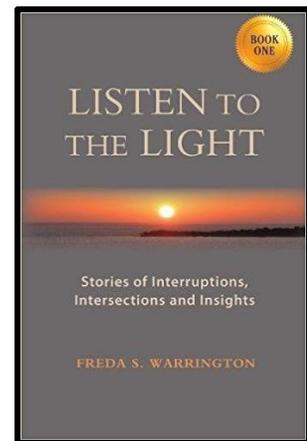
All of the Can Do MS programs, delivered with caring, understanding and commitment, are designed to help people with MS and their families transform challenges into possibilities so that they can live the fullest life possible.

A Visit With Freda Spector Warrington

Freda's life was touched by multiple sclerosis (MS) when her daughter was diagnosed while a college student. At that time she and her family learned everything they could about the disease and that's when they discovered the Accelerated Cure Project (ACP) and its mission to facilitate research efforts to improve diagnosis, optimize treatment and work toward finding the cause and the cure for MS. In her words, "ACP's collaborative approach to research makes so much sense. I hope that their embrace of this scientific paradigm works wonders and gets us answers."

Freda Warrington grew up in Arlington, Massachusetts with her father, the local pharmacist and her mom, a non-practicing attorney. She received her liberal arts education at Vassar and spent most of her career in the health care industry, heading various programs dealing with infant mortality and substance abuse/addiction. An irony, she mentioned, was that her first job after college was as an assistant in the Department of Neurology at MGH doing chart research trying to link MS to a patients' previous attacks of optic neuritis. The year was 1966. Twenty-three years later, her daughter was diagnosed with MS after an initial attack on her vision.

Warrington states that she's been a writer since her first lock and key dairy in childhood. She moved on to her high school newspaper and now has published her first book in February of 2017, "[LISTEN TO THE LIGHT: Stories of Interruptions, Intersections and Insights \(Book One\)](#)." This is a collection of short stories about the unexpected experiences of an everyday life and the wonder/deeper meaning behind them. These "out of the blue" experiences were originally pulled together for her grandchildren but she quickly saw the universality in each story, whether it is about what to do with your treasures when you're old, how to keep meaningful family stories alive, how your loving gifts of food matter, and what to think when an antique bowl shatters spontaneously. One story tells about the strangest of dreams that made a prediction worthy of Alfred Hitchcock.



Freda stresses the importance of preserving the story behind the treasures in our lives, whether it's the secret revealed in a photo rescued from an old frame or the passing along of the history of six generations of owners of an heirloom clock. The bottom line in her stories is that there is wonder everywhere if you will stop to listen and also if there is no answer to a question, it's okay to accept it as given, maybe a miracle, and just say, "wasn't that a great bit of magic", without a need to look behind the curtain. Warrington challenges her readers to capture their own stories on paper and to see just how remarkably universal they are.

Warrington's daughter studied to be an economist at Columbia College and did a stint as a teaching assistant at University of California in Santa Barbara before she became a math teacher in Pennsylvania and California. When she and her husband moved to upstate New

York, she built a farm for her Icelandic horses, chickens, and gardens but primarily breeds Icelandic sheep. With help from her husband and children, she continues to enjoy her life on the farm.

Warrington's second book, *LISTEN TO THE LIGHT: The Daughter's a Farmer* (Book Two) will be released soon.

Warrington is generously donating profits from the sales of her book to the Accelerated Cure Project (ACP). Her donations are matched by the [HERO fund](#) from Shell Oil Company, her husband's former employer. She encourages others to maximize their charitable contributions to ACP through recurring and sustainable donations, seeking out employee matches, and by encouraging others in one's network and beyond to contribute to ACP.

For more information on Freda Warrington's works and her inspiration for capturing your own stories, for book club questions, and for group rates for clubs, please visit her website, www.fredaSwarrington.com.

[LISTEN TO THE LIGHT: Stories of Interruptions, Intersections and Insights](#) can be purchased on Amazon and other outlets.

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