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July 2022 Newsletter

Offering support, care, and hope...*right here at home!*

We are continuing to work in the office to make sure the telephone calls, emails, and office needs are being handled. If you are in need of an in person meeting, please call the office and we will be glad to make arrangements to meet with you. It is important to us that we provide up-to-date information on our website and Facebook page for you.

To receive newsletters, send your email address to: officemanager@tristatems.org

**The mission of the Tri-State Multiple Sclerosis Association
is to enhance the quality of life for individuals living with MS & their families in
Southern IN, Southern IL & Western KY**

Invisible Symptoms of MS

Susan Reynolds RN MSCN

Many MS symptoms are invisible to other people. The symptoms may affect you greatly, but no one seems to notice. This can be very frustrating and upsetting. Dealing with the invisible symptoms of MS can be extremely challenging. The symptoms often go undiagnosed and undertreated, and they are often misunderstood by family, friends, and co-workers.

Which MS symptoms?

Which MS symptoms can seem invisible? Some symptoms are more invisible than others, but invisible symptoms include:

anxiety	bladder symptoms
bowel difficulties	cognitive symptoms
depression	vertigo (dizziness)
fatigue	pain
sexual issues (for men and women)	vision problems
numbness and tingling	heat intolerance
speech and swallowing problems	muscle weakness

Our family and friends aren't mind readers, so perhaps we expect too much from them in figuring out what's going on. Will they know that a grimace on your face means that you are in pain? Will they realize that you cannot be outside in the heat, and will they think that you are rude when you can't come to an outdoor summer picnic? The invisible symptoms can be debilitating to you; but other people will not notice, or they might barely notice.

For me, I know the location of every clean, public restroom in my hometown, because when I go out, I still need to urinate often. Fatigue and cognitive issues can get worse in the summer heat. Sometimes your arms and legs feel heavier and begin tingling when you get too hot.

Many people with MS have fatigue all the time and/or they just suddenly ‘hit a wall’ and have to go home to rest. Your speech can be affected, and you may sound like you are drunk. People can be very quick to jump to conclusions. If you are wobbly or unbalanced while walking, they may assume you’ve had a bit too much alcohol, or they may assume you are on drugs. Chances are that they will not consider MS balance symptoms as a possibility.

The decision to tell someone that you have MS is an individual decision. You are not obligated to tell anyone that you have MS. If you do share with someone, the way you share it with them can make all the difference. If you are scared and emotional, you may get an emotional reaction from them. Maybe you have already explained your MS symptoms to someone, but they don’t ask you about the symptoms, or they don’t remember that you can’t walk for very long, be outside in the heat, or stand for long periods.

It’s not that people don’t care, they just don’t remember. You might have to remind them several times. You might have to ask for special accommodations in your workplace in order to keep working. You might even have to stop working and apply for disability.

Many people don’t understand how these symptoms affect you in everyday life or work life. Think back to when you were first learning about MS. Had you heard of spasticity? Could you explain nerve pain, cognitive issues, or the painful MS hug? These symptoms are hard to understand for someone who does not have MS. You might need to explain more than once so that they can appreciate your difficulties. If it is a workplace problem where you need special accommodations, you will need a note from your Neurologist explaining your limitations.

Therapists can help you sort out how to divulge that you have MS. Support groups can also be helpful. You might ask other people with MS how they handled disclosing their MS to others. **Talking to people who have the disease can validate your own experience and help you feel less alone.** When it comes to dealing with disclosing your MS, a support group is no substitute for working with a good mental health professional.

I have found that many people confuse MS with muscular dystrophy, or they just have no idea what MS is. It might be useful to have some printed materials from the MSAA, the National MS Society, or MS Foundation. Having something published by a national organization, with details about the disease, gives legitimacy to your symptoms (in many people’s minds). It helps educate people who may not understand why you’re using a handicapped space, or who make comments like, “You don’t look like you’re sick.”

It’s also useful to tell the person whether your symptoms are permanent or intermittent (meaning they come and go). It’s important to let people know you’re doing everything you can to manage your symptoms and are under a doctor’s care. This helps head off well-meaning, health advice from friends, family or co-workers. It also shows you’re not making excuses, giving up, or being lazy.

Be sure to share symptoms with your Neurologist as well. Fatigue, depression, anxiety, urinary problems, pain, insomnia, sexual dysfunction and even cognitive issues can all be managed with medications and other interventions. Your Neurologist must be made aware of these problems, and you are the best one to explain how your life is being impacted by these common MS symptoms.

Other professionals can also be of assistance. **Take advantage of various experts such as speech therapists, physical therapists, occupational therapists, psychologists and psychiatrists. These specialists can work with you to create strategies to help you minimize the impact MS has on your life. Talk to your Neurologist about getting a referral for the type of therapy you need.**



**The following is a past article,
but with the intense heat, it is worth repeating!**



Tips for Dealing with Summer Heat

Susan Reynolds, RN, MSCN

July is here! It is time for the worst of the summer heat to start rolling in. I am never ready for it. I choose to do most things indoors in the air conditioning during the summer. I can tolerate heat a little better if I stay out of the direct sunlight. If I go outside, I stay in the shade or do outdoor activities when the sun goes down.

Hot weather or becoming overheated can temporarily worsen MS symptoms. The temporary worsening is due to an increase in body temperature and will usually disappear when the body temperature returns to normal. Getting the body temperature back to normal can be as easy as taking a cool shower, a cool bath, or jumping in the pool.

For people with MS, heat intolerance is felt as increased symptoms, such as: decreased cognitive function, numbness in the extremities, fatigue, blurred vision (known as Uthoff's sign), tremor, or weakness.

What causes heat intolerance? People with MS have plaques or places where demyelination has taken place. Demyelination slows down the transmission of the nerve impulses. An increase in body temp of $\frac{1}{4}$ to $\frac{1}{2}$ of a degree can worsen MS symptoms because heat further impairs the ability of the demyelinated nerve to conduct electrical impulses.

Heat causes only a temporary worsening of MS symptoms; it does not cause permanent tissue damage. As previously stated, the symptoms can be rapidly reversed when the body is cooled.

The following list is intended to help people with MS deal with summer heat. The list is in no way comprehensive, but it contains things that have worked for me and things I want to try.

1. **Air Conditioning:** If an air conditioner is needed for your home because of MS-related heat intolerance, the cost of this equipment may be tax-deductible, if your doctor writes a prescription for it. Air conditioning is the primary way to stay cool on a hot summer day.
2. **Cooling Products:** A large variety of personal cooling products, including different types of vests, neck bands, and bandanas. The Multiple Sclerosis Association of America has a Cooling Distribution Program to supply cooling products to people with MS who need them, but cannot afford them. I have a vest that was made by my mother-in-law! Patterns and instructions for making cooling products are available online.

3. **Avoid Direct Sunlight:** Wear loose clothing, and stay out of the sun. Choose a shady spot, if you must be outdoors. Take along your own battery-operated misting fan.
4. **Don't Blow-Dry Your Hair:** Take time to let your hair dry naturally. If you must blow dry your hair, use the coolest setting possible.
5. **Order a Sandwich:** Instead of soup or something hot, eat only cool foods. Try not to eat cool foods that are high in sugar, such as popsicles and ice cream. This can contribute to fatigue by causing a sudden drop in blood sugar.
6. **Drink Cold Beverages:** Drinking cold beverages can help lower your body temperature. Keep a couple of plastic bottles filled with water in your freezer to take along in the car. Drink it as they melt.
7. **Pre-Cool:** Cool down with a cold shower before activities. Getting chilly before heading outside buys time before you feel the heat. You will have to experiment with how cool of a shower you can endure and how much it helps you, but you might be surprised at the increase in your tolerance for the heat.
8. **Go For a Swim:** Pools with water that is 85 degrees or cooler are ideal for exercising or just relaxing outside.
9. **Use a Microwave:** Don't use your oven in the summer. If you use an oven, don't open the door to check on the food. The blast of hot air is enough to trigger symptoms.
10. **Take an Aspirin:** Some Neurologists suggest taking one regular strength aspirin before going out in the heat to keep your core body temperature down.
11. **Get "The Handicapped Tag":** If you are ambulatory, it may not have occurred to you to get a disabled parking placard to avoid crossing blazing hot parking lots in the summer. Some of you might be resistant to getting one. A "Tag" can be a lifesaver during the hot summer months. Get one, just in case you need it.
12. **Hydrate!** Drink plenty of cold water! This may be the most important way to stay cool.

For information and to apply for FREE a cooling vest go to: mysaa.org. MSAA has free cooling vests for anyone with MS who completes an application and who fits the income requirements. Or call: 800-532-7667.

Upcoming Educational Programs

The following pharmaceutical company has scheduled educational programs in the tri-state area. For more information, visit their websites, or call them for dates and locations.

EMD Serono has scheduled the following educational program: **Wednesday, July 27th** at 12:00 p.m. (noon), The Patio, Tell City, IN; and a Dinner program at Biaggi's, Evansville, IN at 6:00 p.m. **Speaker: Dr. Mark Janiski**, Zionsville, IN.

To register for these EMD Serono programs go to MAVENCLADevents.com or call 1-855-685-0738.