

October 2019 Newsletter



Overcoming the Challenges of Progressive MS

MS is a variable, unpredictable disease. Its symptoms differ from person to person and from time to time in the same person. Those living with progressive MS experience a worsening of symptoms over time that gradually results in functional loss and increasing disability. To say that living with progressive forms of the disease is difficult would be a huge understatement. Progressive MS is relentless, unfair, painful and debilitating. It never takes a day off or offers much in the way of relief. For many, living with progressive MS involves constantly managing MS symptoms and treatments, prioritizing what needs to be done in a day and learning how to best deal with the uncertainty of the future. While there is no approved treatment that can reverse the damage progressive MS causes, there are ways to overcome the challenges it poses.



As discussed in our [June 2019 newsletter](#), approximately two thirds of people with MS have difficulty walking. Gait difficulties tend to worsen as the disease progresses. Assistive technology offers a wide variety of tools and devices that allow individuals struggling with disability to stay active and ambulatory. Modifications such as ramps and

grab bars may be necessary to improve accessibility and safety at home. Rehabilitation professionals can help recommend appropriate devices and home modifications to optimize one's independence. [AbleData](#) is an online database of information on thousands of assistive technology products that can be researched by type or topic. The Multiple Sclerosis Association of America's (MSAA's) [Equipment Distribution program](#) offers a wide variety of these products free of charge to individuals with MS who qualify for assistance. Something as simple as rearranging one's home can make life easier, for example, putting frequently used things within easy reach. The National MS Society's (the Society's) brochure entitled "[At Home With MS](#)" offers many ideas on adapting one's environment to the changes that progressive MS may bring.

A high percentage of people with MS are sensitive to heat and experience a worsening of symptoms, or new symptoms, when their body temperature rises. For this reason, many avoid hot showers or baths, or use fans and air-conditioning to stay cool in hot weather.



Some people with MS tend to get overheated when they exercise. If this is the case, doing outdoor activities during the cooler hours of the day, exercising in an air-conditioned gym, or swimming may be helpful. Other helpful strategies include staying hydrated, wearing a [cooling vest](#) or neck wrap, taking cool down breaks, and staying out of direct

sunlight. MSAA's [Cooling Distribution program](#) offers cooling vests and other accessories to help cool the neck, wrists and ankles. MSAA provides these products at no charge and items are shipped directly to the client. Some people with MS experience an increase in symptoms in cold weather, too. Therefore, it's also important to try to stay warm when temperatures are frigid. It may be helpful for people with progressive MS to keep a journal to track what makes their symptoms worse (the idea being once triggers are determined, they can be avoided).

As mentioned in our [March 2019 newsletter](#), sleep is essential to functioning well, mentally and physically. It's essential for people with progressive MS to practice good sleep hygiene. This can be done by sticking to a consistent sleep schedule, keeping the bedroom dark, quiet, and cool, avoiding too many fluids before bedtime and creating a relaxing bedtime routine. It's also important to address any specific issues that are interrupting sleep or making it hard to fall asleep. Anxiety, muscle spasticity, frequent

help a person have more energy and also prevent other chronic health conditions, such as heart disease. Exercise is important for everyone with MS, both for fitness and for function. Regular exercise promotes flexibility, can improve balance, and may also help with common MS complications, such as constipation, trouble sleeping, and cognitive issues. Those with advancing disability may benefit from working with a physical therapist to identify exercises that will strengthen muscles that are weak and help reach specific goals, such as walking more easily or improving [foot drop](#). It may be necessary to modify favorite activities or find new ones to enjoy. In either case, it's important to stay active. Smoking is a big risk factor for developing MS as well as for the worsening of the disease. According to the [National MS Society](#), this includes exposure to secondhand smoke. While smoking is unhealthy for everyone, it's a particularly harmful lifestyle choice for people with progressive MS. [Research](#) suggests stress may also trigger MS symptoms or make them worse. Having any chronic illness is likely to increase stress levels and MS is no exception. Reducing stress through meditation, or other stress-reduction practices (yoga, exercise, connecting with others or just maintaining a sense of humor, to name a few) may help improve quality of life, as well as possibly slow disease progression.

It's important for people with progressive MS to maintain their physical health. As discussed in our [July 2019 newsletter](#), people with MS have been found to have more co-existing health conditions than the general population. These other illnesses, called comorbidities, not only compromise one's overall health, they are also associated with more rapid MS progression. Therefore, preventing or effectively treating comorbidities is essential to improving MS outcomes. It's important to maintain an ongoing relationship with a primary care provider to ensure appropriate preventive health measures are followed (such as flu shots and recommended health screenings) and any comorbidity is adequately identified and treated. The complexity of MS and the multitude of comorbid conditions that individuals with MS may experience require coordinated, comprehensive care with many clinicians taking a team approach. It is essential for people with all forms of MS to be engaged with a diverse team of healthcare providers with the expertise to manage their MS and any other health conditions they may have.



Maintaining one's mental health is key to overcoming the challenges posed by progressive MS. Spiritual beliefs can play a significant role in this regard. Many rely on prayer to get through difficult times. Religious advisers may offer important

advice and support. As discussed earlier, treating depression is very important. Some find solace in simply accepting their “new normal” and choosing to move forward every day. Increasing disability often means not being able to participate in activities once enjoyed. Maintaining a good attitude and staying thankful for remaining abilities may help adjust to these changes. If possible, viewing limitations as hurdles to go over rather than insurmountable walls may help brighten one’s outlook. If it’s not possible to make it over a certain “hurdle”, figuring ways around it instead of giving up may be a way to boost morale. Keeping busy can be a good way to maintain a sense of normalcy. For those who can’t work, volunteering, starting a new hobby, or adopting a pet are good ways to fill idle time. Going on vacation can go a long way toward improving mental health. It may take extra planning, but vacations can be as much fun as ever. Just remember to slow down, keep limitations in mind (don’t try to visit 5 cities in one week) and be flexible. As discussed in our [June 2019 newsletter](#), it’s important for people with MS to keep their brain engaged and stimulated. Mentally challenging activities, such as crossword puzzles, word games, memory games, taking classes or reading, all help to keep one’s mind sharp. Staying socially active also helps mental function and staves off loneliness at the same time.

The challenges of progressive MS can be very isolating, however it’s important not to face them alone. A good support system is needed. Connecting with others who are affected by the same challenges can help one learn new information and discover different strategies for coping or dealing with problems. This fellowship allows one to both give and receive support (both of which are very therapeutic). The Society offers a number of resources to



help fend off isolation and help people with progressive MS find the support they need.

The [MS Navigator program](#) can provide information to individuals living with the disease, help one find a support group or healthcare provider, provide wellness strategies or even crisis intervention in times of need. [MSconnection.org](#) is a social networking website and community that enables those living with MS to interact in a safe and secure environment. Community members can connect based on things they may have in common, such as symptoms, treatment, where they live, or mutual interests. The Society’s [Peer Connections program](#) offers someone who has “been there” to provide tips, suggestions and emotional support to help one navigate the trials MS may impose. The [MSFriends program](#) offers the opportunity to connect with volunteers living with disease. They know

first-hand what it is like to live with MS and can help deal with any changes brought about by the disease. The Society also offers a number of [local support groups](#) that bring together people with similar experiences to learn from and support each other. The [Edward M. Dowd Personal Advocate Program](#) offers case management services in situations where needs are complex and support systems are lacking.

Overall, it's important for people living with advanced MS to find ways to make each day a little easier. Some adopt a different strategy of doing things, such as pacing activities, or using a tool that makes a specific task easier (for example, a jar opener). Online shopping saves time and energy to purchase essentials and other items one may wish to buy. For those that can, hiring a housekeeper to help with cleaning and laundry makes a big difference. For those that are employed, working from home, whenever possible, is a wonderful way to simplify life. In all cases, taking breaks when one starts to feel fatigued is essential.

MS isn't a disease that can be completely controlled and living with it is a process. Despite the best management strategies, interventions and treatments, the disease may take its own course and disability may occur. Some days may feel manageable, while other days may not. For some people, having MS puts their priorities into perspective; for others, it may feel more like an obstacle in the way of all their plans and dreams. For anyone, feelings of sadness, loss, anger or anxiety are common and may occur at any time over the course of the disease. It's important for those living with persistent symptoms and advancing disability to arm themselves for the hard days, but also to celebrate the good days. Staying resilient may be a challenge, but there are ways to make this easier. Reach out to resources that are available for people with MS. Find meaningful ways to be productive and fulfilled. This may involve developing new mental, emotional and spiritual "muscles." Keep in mind these goals may take time. But remember people with progressive MS can, and do, pass through dire periods. Some find resilience in their faith, support groups or by tapping their sense of humor. Others do so with the help and support of family and friends. Keep in mind many



things can be done to maintain good health, treat MS symptoms, improve quality of life and maximize the ability to function.