

September 2019 Newsletter



Newly Diagnosed With MS?

A new MS diagnosis can be scary and overwhelming. For some, it's a relief to finally understand the reason for puzzling symptoms that may have been an issue for quite some time. For others, MS manifests itself suddenly and the diagnosis comes as a shock. For most, the disease adds an element of uncertainty to the future. It's easy to feel isolated and lonely while facing an MS diagnosis, even with a loving family and supportive friends. These loved ones may not fully understand what living with MS is really like. There are a variety of strategies one can try to weather the storm. In addition, a number of MS organizations offer a wide array of resources and support to help those newly diagnosed with the disease better understand its scope and rise to meet its day-to-day challenges.



When faced with an MS diagnosis, there are a number of things one can do to help cope with this new knowledge and manage the disease. It's important to consider who to share this information with. One should not feel obligated to tell everyone. Announcing the news to an employer could have negative implications. People newly diagnosed with MS should pick the people who will be most supportive and helpful as they learn to live with the disease. There are many myths and misconceptions about MS. Many people find it

helpful to learn as much as possible about the disease. Knowing the facts may help make an MS diagnosis less scary. It helps to understand that MS symptoms are unpredictable. No two people have exactly the same symptoms, and one may have different symptoms from time to time. Over the course of the disease, some may come and go, while others may be long lasting. Keeping a record of MS symptoms is another useful practice. This not only helps physicians determine how the disease is progressing and if prescribed treatments are working. It also helps them recognize MS relapses. Certain triggers, such as stress, lack of sleep, infection and overheating, are thought to bring on MS relapses, or make them worse. It's important for people with MS to avoid these triggers.



MS is a lifelong disease, so it's essential for people living with the disease to find the right doctor (one they are comfortable working with). [Research](#) shows the disease is more likely to progress and possibly lead to disability if treatment isn't started

early in the disease. As discussed in our [August 2017 newsletter](#), some people with MS turn to alternative treatments to manage their symptoms, most often in combination with their prescribed MS treatments. These therapies are often used for pain relief, fatigue and stress.

The National Multiple Sclerosis Society (the Society) is a non-profit organization based in New York City with chapters located throughout the United States. The organization funds research, provides education, and sponsors services that help people with MS and their families. They offer a number of resources to educate the newly diagnosed about many aspects of the disease, including a variety of informative brochures (highlighted below).



National Multiple Sclerosis Society Brochures

[Diagnosis – The basic facts](#) – Explains typical MS signs and symptoms, the tests used to diagnose MS (including how to prepare for an MRI), as well as the criteria for diagnosis.

[What is Multiple Sclerosis?](#) – Includes information about MS, including its symptoms, treatment, and what happens in the course of the disease.

[Choosing the right healthcare provider](#) – Outlines steps people with MS should take when choosing a healthcare provider and some tips for the first visit with them.

[The disease modifying medications](#) – Provides information on the disease-modifying treatments (DMTs) for MS, including how each one is taken, benefits and side effects. This brochure also includes information on financial assistance programs for DMTs and other medications for MS symptom management.

[Disclosure – The basic facts](#) – Discusses whom to tell about an MS diagnosis, the timing of the conversation and how much to reveal in both personal and work situations.

[Connecting with others living with MS](#) – Outlines resources available from the Society that can help one connect with other people with MS who may be in a similar situation.

The Society also offers a number of informative videos (for those who prefer this format).

National Multiple Sclerosis Society Videos

[What is MS?](#) – Explains the damage MS causes in the brain and spinal cord, which is what causes its varied and unpredictable symptoms.

[Why does someone get MS?](#) – Covers the risk factors for MS and some theories surrounding why one person or family member gets MS, while another doesn't.

[Tests for diagnosing MS](#) – Describes the tests that are run to confirm a diagnosis of MS, as well as rule out other conditions that may mimic MS.

[Magnetic Resonance Imaging](#) – Describes magnetic resonance imaging (MRI), one of the main tests used to determine a diagnosis of MS.

[A Diagnosis of Probable MS](#) – Explores what a diagnosis of probable MS means and when a person may know with certainty they have the disease.

[Coping with a diagnosis of MS](#) – Answers the question, “What can an individual do to make a diagnosis of MS easier to deal with?”

[Getting a second opinion](#) – Covers the importance of getting a second opinion on a non-diagnosis of MS in the presence of MS symptoms.

Numerous helpful resources can be also found on the Society's website. The [Knowledge is Power](#) (KIP) section of the website contains a free, downloadable educational series for people newly diagnosed with MS and their families. The program provides up-to-date facts about many aspects of MS, including MS treatments, employment, parenting, and relationships in the context of MS. KIP also has a section for family, friends and loved ones as they begin a new chapter living with the disease. The cost of MS medications and treatments can be a burden to those with inadequate insurance coverage. The Society's website also includes a number of [patient assistance programs](#) available to those currently taking or considering starting an MS medication.



As discussed in our [May 2018 newsletter](#), the [Multiple Sclerosis Association of America](#) (MSAA) is a nonprofit organization dedicated to improving the quality of day-to-day living for everyone affected by MS. They do this by providing a wide range of valuable services to the MS community free of charge. Their website contains [information](#) for those newly diagnosed with MS, as well as links to educational videos and webinars.

MSAA videos and webinars

[What is MS?](#) – Provides an overview of the disease, its history, and treatment information.

[The MS Process](#) – Explains how MS develops in the body.

[Diagnosing MS and monitoring disease activity](#) – Spells out the use of MRI to diagnose MS and the importance of clinical exams and patient feedback throughout the course of the disease.

[Relapse Management](#) – Describes the definition of an MS relapse, the decision to treat or wait for symptoms to resolve, and possible treatment options.

[FDA-Approved long-term treatment for MS](#) – Reviews the injectable, oral, and infusion therapies approved for MS, options for treating patients with different types of the disease; and important factors to consider when making a treatment decision.

[Wellness tips for MS patients](#) – Details the importance of wellness strategies including nutrition, exercise and sleep to help improve a person’s overall quality of life.

[Possible causes of MS](#) – Discusses theories behind infection, genetics, diet, and changes in the [microbiome](#) as possible causes for MS.

[Who gets MS?](#) – Explains the prevalence of MS in the United States and various factors that may influence one’s chances of getting MS, including gender, age and geography.

[Types of MS](#) – Provides an overview of relapsing-remitting MS and progressive forms of MS.

[The importance of long-term treatment in MS](#) – Discusses the goal for long-term MS treatment and the importance of shared decision-making to ensure the best health outcome.

[MS Symptoms](#) – Describes the physical, cognitive, and “invisible” symptoms of MS.

[How MSAA can help](#) – Provides an overview of MSAA’s supportive services for the MS community.

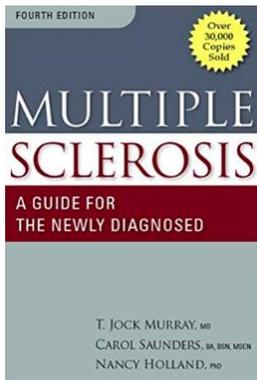
MSAA offers a variety of other resources that may shed light on questions those seeking to learn more about MS may have. Their [S.E.A.R.C.H. Program](#) helps individuals starting or changing MS treatments choose which medication to take in order to achieve the best treatment outcome. Each letter of the program’s acronym represents an important topic that should be considered when making this decision – safety, effectiveness, access, risks, convenience and health outcomes. The MSAA [Lending Library program](#) offers a comprehensive selection of books and a variety of DVDs that cover disease and symptom management, wellness, personal stories from people living with MS, care partner issues, and many other important topics. Their lending policy makes these resources readily available. Participants can borrow one title at a time for up to 45 days. MSAA covers all outgoing and return mailing costs. In addition, MSAA offers an extensive library of on-demand videos, webinars and webcasts (in addition to those listed above) that offer a wealth of information that can be conveniently accessed online. [MS Conversations](#) is the official blog of MSAA. It includes posts from guest bloggers living with MS, as well as

interactive discussions on topics of importance to people living with the disease. This blog is a good resource for people newly diagnosed and looking for a full picture of life with MS.

As discussed in our [August 2017 newsletter](#), [Can Do MS](#) is a nonprofit organization based in Avon, Colorado whose mission is to provide every person affected by 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 offers a webinar, [Managing MS Early: Get Ahead of the Disease](#) that may be helpful to those newly diagnosed with the disease. As the name implies, this webinar covers how to stay proactive and get ahead of the disease. It offers suggestions on how to manage the physical, emotional and social changes MS may introduce into one’s life.



A number of books are available that may be useful resources for those that would like to educate themselves about the implications of an MS diagnosis. For example, [MS: A Guide For The Newly Diagnosed](#) is a guide to learning about the disease, its potential impact and the medical treatments available for managing it successfully (including alternative treatments). [The First Year: Multiple Sclerosis: An Essential Guide for the Newly Diagnosed](#) was written by Margaret Blackstone, who was diagnosed with MS in 2000. When she learned she had MS, she educated herself about the disease. In her book, as a patient-expert, she guides those newly diagnosed step-by-step through their first year with MS.

Whether an MS diagnosis feels devastating or is a welcome explanation of mysterious symptoms, coming to terms with this life change can be challenging. A number of MS organizations offer a wide variety of resources and support to help those newly diagnosed with the disease better understand its scope and rise to meet its day-to-day challenges. With the help of these valuable resources, it is possible to lead a fulfilling life with MS.

