MSAA's Mission:
The Multiple Sclerosis Association of America (MSAA) is a leading resource for the entire MS community, improving lives today through vital services and support.

To help support MSAA's vital programs and services, please visit support.mymsaa.org/donate or call (800) 532-7667.

To learn more about MSAA's Swim for MS fundraising initiative, please visit SwimForMS.org or call (800) 532-7667, extension 157.

Stay Connected with MSAA:
Facebook, Twitter, Instagram, Pinterest, Google+, YouTube, LinkedIn

Copyright © Multiple Sclerosis Association of America, 2018
Funds for the printing of this publication have been generously provided through grants from Sandoz and Teva.

History

The fact that MS symptoms flare up and subside, combined with the unpredictability of symptoms, has made MS a difficult disease to recognize, define, and treat. Since the late 1300s, individuals with a progressive illness suggestive of MS have been observed. Not until 1868 did the famous neurologist, Jean-Martin Charcot, lecture on the features of MS and give it a name.

Throughout the 1800s and 1900s, hundreds of therapies were tried, without success, in the treatment of multiple sclerosis. In 1951, cortisone (a steroid) was first used to treat MS relapses (also known as exacerbations, attacks, or symptom flare-ups). Cortisone was found to reduce the severity of the relapse and to shorten its duration, but it had no long-term effects on the disease.

The first drug proven to be effective in the long-term treatment of MS received approval by the United States Food and Drug Administration (FDA) in 1993. Since that time, as of early 2018, 16 long-term treatments (or brands) have been approved for relapsing forms of MS. One of these 16 medications is also approved to treat primary-progressive MS.

Please note that many more experimental treatments are currently under investigation for relapsing and/or progressive forms of MS, some of which may be approved in the near future – adding to the 16 already-approved treatments. These long-term treatments are also referred to as disease-modifying therapies (DMTs).

While these medications do not cure MS, they do work to slow disease activity as well as reduce the severity and frequency of flare-ups. Additionally, these DMTs may delay disease progression, delay disability, and increase longevity.
Multiple sclerosis (MS) is a disease of the central nervous system (CNS). The CNS consists of the brain, optic nerves, and spinal cord. With MS, areas of the CNS become inflamed, damaging the protective covering (known as “myelin”) that surrounds and insulates the nerves (known as “axons”). In addition to the myelin, over time, the axons and nerve cells (neurons) within the CNS may also become damaged. MS is thought to be an autoimmune disease, where the body’s own white blood cells, known as lymphocytes, become misdirected and attack the body’s own myelin and eventually the axons.

The damage to the protective covering and also to the nerves disrupts the smooth flow of nerve impulses. As a result, messages from the brain and spinal cord going to other parts of the body may be delayed and have trouble reaching their destination – causing the symptoms of MS. Each person with MS may experience different types and severity of symptoms – and some may experience only one or two symptoms, while others may experience a combination of symptoms.

Areas of inflammation and damage in the CNS are known as “lesions.” The changes in size, number, and location of these lesions may determine the type and severity of symptoms. Disease activity may also be evaluated from these changes in the size or number of lesions. Frequently, MS may be “clinically silent,” showing no increase in symptoms, yet continuing to show signs of disease activity within the CNS, as seen on magnetic resonance imaging (MRI) – an important evaluative tool.

For individuals with relapsing forms of MS, early and continued treatment with a disease-modifying therapy (DMT) can often slow the “clinically silent” disease activity in the brain, reducing the size and number of active lesions. This is one reason why most neurologists recommend that individuals with relapsing forms of MS begin treatment as soon as possible after the diagnosis is established. Treatment may now also be recommended for a portion of those with progressive MS as well as for individuals with clinically isolated syndrome (CIS). However, treatment cannot be effective unless it is taken exactly as prescribed and without missing doses, so adherence is critical.

In addition to the lesions, areas of thick scar tissue may eventually form along the areas of permanently damaged myelin. These areas of scar tissue are referred to as “plaques.” The term “multiple sclerosis” originates from the discovery of these hardened plaques. Multiple refers to “many;” sclerosis refers to “scars.”

Lesions and plaques are viewed on a magnetic resonance imaging (MRI) scanner. This technology is used to help diagnose MS and evaluate its progress at various intervals. The MRI and other tools are described in the section titled, “Diagnosing MS and Evaluating Disease Activity,” beginning on page 10 of this booklet.
Who Gets MS?

For decades, the number of people living in the United States with MS has been estimated at 400,000. However, no system or database exists to provide an exact figure, and some sources are now estimating that the population of individuals with MS in the United States may be much higher than this earlier number. Estimates for the global MS population typically range between 2.3 and 2.5 million. As more information becomes available, MSAA will provide updates on these estimates.

Most people with MS experience their first symptoms and are diagnosed between the ages of 15 and 50, although individuals of any age may be diagnosed with MS. MS in childhood and adolescence is now being diagnosed more frequently, due in part to an increased awareness that children can get MS. Known as pediatric MS, diagnosis in children is still extremely involved, as experts have identified more than 40 common diseases that may initially behave similarly to early MS. In the United States, previous estimates ranged from 7,000 to 10,000 children and teens with MS. Similar to other population figures, MSAA will provide updates as more information becomes available.

The distribution of this disease is not totally random. On average, with relapsing forms of MS, women are three times more likely than men to develop this disorder. However, with the primary-progressive form, genders are more equally divided.

Geographically, people who live farther from the equator (in more temperate climates) have a higher risk of developing MS than people living in hotter areas near the equator, or in very cold areas near the north or south poles. Individuals living beyond the 40-degree mark north or south of the equator are far more likely to develop MS, and this is especially true for people in North America, Europe, and southern Australia. The degree of risk associated with where someone lives as a child will remain throughout his or her life.

MS is very rare in Inuit populations living in the far north. Asia continues to have a lower incidence of MS. More prevalent among those of northern European or Scandinavian ancestry, Caucasians have a higher incidence than those of African heritage to develop MS. One study, however, indicated that African Americans are at a higher risk of MS than originally thought, but more research is needed to confirm this finding.

African Americans and Asians tend to have more symptoms at the time of diagnosis, which are usually limited to the optic nerves and spinal cord, and this is termed “opticospinal MS.” This means that African Americans and Asians may experience more problems with vision and mobility, versus other common MS symptoms.

African Americans may be older at disease onset, and the disease course tends to be more aggressive, with more frequent relapses and higher lesion volume. Additionally, African Americans are thought to respond less to disease-modifying therapies, although studies are being conducted to see which medications are the most effective for this ethnic group.

Hispanic Americans are often diagnosed at an earlier age than Caucasian Americans, and a larger percentage are diagnosed with RRMS versus PPMS. They are more likely to present with optispinal MS, optic neuritis (inflammation along the optic nerve), and/or transverse myelitis (causing inflammation in one location across both sides of the spinal cord).

Hispanic Americans have a much lower risk of MS compared to Caucasian Americans and African Americans. However, clinical observation reveals greater spinal-cord involvement, which more significantly affects ambulation, but more studies are needed to confirm this observation.

While MS is not contagious or hereditary, MS susceptibility is increased if a family member (blood relative) has MS. The average risk of developing MS in the United States is one in 1,000, or one-tenth of one percent. For first-degree relatives (such as a child or sibling), the risk increases to three or four percent. This is not true for adopted children or half siblings (who do not share the same parent who has MS), whose risk is the same as unrelated individuals.

In situations where one identical twin has been diagnosed with MS, the other twin has a 31-percent risk of developing the disease. If MS was strictly hereditary, when one identical twin has MS, the other identical twin would have a 100-percent risk of getting MS. The risk for twins who are not identical is five percent – similar to that of other siblings. Other groups of individuals who appear to have an increased risk of developing MS include those who smoke cigarettes, individuals with less exposure to sunlight and with lower amounts of Vitamin D, as well as people living in cleaner environments with fewer parasites. These findings are explained later on page 8, under “Possible Causes of MS.”
Types of MS

Multiple sclerosis (MS) affects each person differently. The most common types of MS are:

- Relapsing-Remitting MS (RRMS)
- Secondary-Progressive MS (SPMS)
- Primary-Progressive MS (PPMS)

Initially, most people with MS experience symptom flare-ups, which are also known as relapses, exacerbations, or attacks. When someone experiences a relapse, he or she may be having new symptoms or an increase in existing symptoms. These usually persist for a short period of time (from a few days to a few months) and afterward may remain symptom-free for periods of months or years. This type of MS is referred to as relapsing-remitting MS (RRMS). Approximately 80 to 85 percent of people with MS are initially diagnosed with this form of the disease.

Over time, RRMS may advance to secondary-progressive MS (SPMS). This form of MS does not have the dramatic variations in symptoms that RRMS does, but rather has a slow, steady progression – with or without relapses. If relapses do occur, they usually do not fully remit. Without treatment, approximately half of individuals with RRMS convert to SPMS within 10 years. However, with the introduction of long-term disease-modifying therapies (DMTs), fewer individuals advance to this latter form of the disease.

Individuals who are not initially diagnosed with RRMS may be experiencing a more steady progression of the disease from the onset. Approximately 10 percent of the MS population is diagnosed with primary-progressive MS (PPMS), where individuals experience a steady worsening of symptoms from the start, and do not have periodic relapses and remissions.

A small percentage of individuals are initially diagnosed with a less common form of MS known as progressive-relapsing MS (PRMS). This type of MS steadily worsens from the onset, but symptom flare-ups – with or without remissions – are also present. However, as the different forms of MS are further studied, redefined, and reclassified, the label of progressive-relapsing MS is being used less frequently. Other types of MS exist, but these are uncommon and different terminology may be used. Listed below are these less-common forms of MS.

- “Fulminate MS” is a rapidly progressive disease course with severe relapses within five years after diagnosis; also known as “malignant MS” or “Marburg MS,” this form of very active MS may need to be treated more aggressively than other forms.
- “Inactive MS,” sometimes labeled as “benign,” shows little or no change after 15 years; however, progression may occur at a later time.
- “Burned-out MS” is another type of inactive MS; it is a controversial term used to describe MS patients whose MS progression slows dramatically later in life.

Prior to an MS diagnosis, individuals with “possible MS” may often fall under the parameters of one of two syndromes. The first is clinically isolated syndrome (CIS), where someone may have experienced symptoms of MS for the first time, and an MRI may show evidence of MS, but a diagnosis cannot be confirmed at that time. Disease-modifying therapies are often used to treat CIS in an effort to delay or prevent the eventual diagnosis of MS.

The second syndrome is radiologically isolated syndrome (RIS), which is the term used when someone has an MRI performed for an unrelated reason, and shows evidence of MS on the MRI scan, but does not have any signs of MS symptoms. As with CIS, more evidence will be needed in the future to determine if someone with RIS may be diagnosed with MS.
Possible Causes of MS

Researchers have studied a variety of possible causes for multiple sclerosis (MS), and a combination of factors appears to be involved. A popular theory looks at commonly known slow-acting viruses (one that could remain dormant for many years), such as measles, herpes, human T-cell lymphoma, and Epstein-Barr. After being exposed to one of these viruses, some researchers theorize that MS may develop in genetically susceptible people.

In the absence of a solid understanding of the mechanisms that underlie MS, no specific genes for MS have been identified. Genes have some role in susceptibility to MS, but the exact mechanisms remain unclear.

The list of genes that have been investigated for MS susceptibility is long and continually expanding. Linkage studies show that the major histocompatibility complex (MHC), which is a cluster of genes on chromosome 6, has the strongest genetic effect in MS. Additionally, other genes make considerably weaker contributions to MS disease risk.

Some scientists are looking for a connection between MS and nutritional factors, including fat intake, as well as deficiencies in fish oil and Vitamin D. The idea that a diet rich in saturated fat may increase one’s risk of getting MS, as well as worsen his or her disease course, has been a popular theory for several decades. In addition to food and supplements, Vitamin D is also derived from sunlight. Reduced sunlight may be involved in the development of MS.

As noted earlier, populations living closer to the equator have a lower incidence of MS. A popular theory is that those living closer to the equator are exposed to more sunlight and therefore are less likely to experience a Vitamin D deficiency. Studies suggest that low levels of Vitamin D may increase one’s risk of MS. Conversely, the Nurses’ Health Studies (I & II) found that women who were taking 400 IU or more of Vitamin D daily had a lower risk of developing MS.

Salt is also under investigation as a possible factor in MS. One study showed that high dietary salt was found to increase autoimmune neuro-inflammation in animal models. A separate study revealed that higher salt consumption was associated with increased clinical and MRI disease activity in people with MS.

Parasites are a possible risk-reduction factor in the development of MS. The parasites in this instance are “helminths,” which refer to a wide variety of worms. Some are thought to be harmless, and many people had pinworms as children. Research has found that parasites can modulate the immune system and dampen its responses. People who have parasites are less likely to be diagnosed with MS, and as conditions in different countries become cleaner – with fewer parasites – the number of individuals being diagnosed is increasing in these parts of the world. Parasites are less common in the United States, which may contribute to the higher incidence of MS in this country. However, some types of worms could possibly make MS worse, so more research is needed.

In recent years, researchers have found that interactions between a person’s microbiome and his or her immune cells may contribute to the development and severity of many disease states – including MS. The microbiome refers to the many millions of bacteria that reside in a person’s body, with current research focusing mainly on the bacteria that live in the intestines (referred to as “gut microbiota”). Specifically, researchers have hypothesized that imbalances in the number or types of different strains of bacteria could potentially cause the immune system to be inappropriately activated to develop an autoimmune disease. Multiple groups are currently conducting research on the microbiome and its potential connection with MS.

Another factor linked to MS is cigarette smoking. One study shows that women who smoke are 1.6 times more likely to develop MS than women who are non-smokers. Individuals with MS who smoke also appear to be at a much greater risk of experiencing a more rapid progression of their disease.
Diagnosing MS and Evaluating Disease Activity

Diagnosing and evaluating MS disease activity is most reliably done by neurologists through a neurological history and examination. Tests that can indicate MS and rule out “MS mimickers” (other diseases that resemble MS but have other causes) are also performed.

Concerning an MS diagnosis, many diseases may mimic MS. For example, Vitamin B-12 deficiency may cause “subacute combined degeneration of the spinal cord” and pernicious anemia (a condition that occurs as a result of the body not making enough healthy red-blood cells). If significant brain lesions are not found on an MRI, “Recurrent Transverse Myelitis” (lesions in the spinal cord only) may be a possibility. Other common MS mimickers include Lyme disease, stroke, lupus, migraines, chronic fatigue syndrome, fibromyalgia, carpal tunnel syndrome, and more. Individuals without a definite diagnosis of MS may need an expert with more information to make the diagnosis. A second opinion at an MS center can be of help.

Lesions (areas of inflammation and myelin damage in the brain and/or spine) may be viewed on a magnetic resonance imaging (MRI) scan. The MRI uses a computer, radiofrequency stimulator, and a large electromagnet to provide a picture of the brain and/or spine. While the picture looks a bit like an x-ray, it uses a different technology to show other details, and the MRI does not expose the patient to any radiation. For people with multiple sclerosis, the MRI is used to evaluate the size and location of lesions. Inflammation can be better evaluated with gadolinium (or contrast) enhancement – a type of dye given to the patient via injection prior to the procedure. The MRI, particularly with gadolinium enhancement, allows doctors to measure disease activity within the central nervous system (brain, optic nerves, and spinal cord). Test results can help determine the effectiveness of a disease-modifying therapy (DMT), or to get an “inside view” of a patient’s disease status.

Another tool that is sometimes used in the diagnosis of MS is a lumbar puncture (also known as a spinal tap). This is a procedure where a very thin needle is inserted at the base of the spine and a small amount of cerebrospinal fluid (CSF) is collected. CSF is the liquid that surrounds the brain and spinal cord. By collecting a small amount of this fluid, laboratory testing may be performed to evaluate cellular and chemical abnormalities. However, even if no evidence of MS is found in the CSF, this does not rule out MS as a possible diagnosis.

Evoked potential (EP) tests may also be used to help diagnose MS, if further support is needed. These measure the speed of the brain’s response to visual, auditory (sound), or sensory (feeling) stimuli, using electrodes taped to the patient’s head. Delayed responses can indicate possible damage to the nerve pathways.

Additional tools are available to measure disease activity. These are used mainly in clinical trials to help evaluate disease progression as well as changes in specific symptoms, such as fatigue, strength, mobility, vision, cognition, and others. The most widely known scale among the MS community is the Kurtzke Expanded Disability Status Scale (EDSS). It uses whole and half numbers from one to 10 to measure degree of disability, largely in terms of mobility.

Another measurement system is the MS Functional Composite (MSFC) scale. This measures lower-extremity function with a Timed 25-Foot Walk, upper-extremity function through the 9-Hole Peg Test (9-HPT), and cognitive function, using the Paced Auditory Serial Additions Test (PASAT).
Relapse Management

Relapses, also referred to as exacerbations, attacks, flare-ups, episodes, or bouts, are initially experienced by most people diagnosed with multiple sclerosis (MS). Relapses occur with relapsing-remitting and sometimes secondary-progressive forms of MS. Relapses also occur with progressive-relapsing MS, although as mentioned earlier, some experts are reclassifying this form of MS into one of the other more common forms. Relapses do not occur with primary-progressive MS, although people with PPMS may experience day-to-day fluctuations in how they feel.

During a relapse, inflammation is occurring along the nerves and the myelin, causing patients to have a temporary worsening or recurrence of existing symptoms and/or the appearance of new symptoms. This can range from a few days in duration to a few months, followed by a complete or partial recovery (remission). Acute physical symptoms and neurological signs must be present for at least 24 to 48 hours, without any signs of infection or fever, before the treating physician may consider this type of flare-up to be a true relapse.

A pseudoexacerbation is a temporary worsening of symptoms without actual myelin inflammation or damage, brought on by other influences. Examples include other illnesses or infection, exercise, a warm environment, depression, exhaustion, and stress. When symptoms flare, checking for a fever is important, since even a minor infection and slight increase in temperature can cause symptoms to appear.

Relapses are usually treated with a high-dose course of powerful corticosteroids (a type of steroid) over a period of three to five days. These are given by intravenous (IV) infusion, administering the drug directly into the bloodstream for a quicker response. Some doctors prescribe oral steroids after the high-dose treatment, to ease the patient off of the medication. These are usually tapered over one to two weeks. Another FDA-approved option is Acthar® Gel, which contains a highly purified form of the hormone adrenocorticotropic (ACTH). It is given once daily for two to three weeks and is injected either into the muscle or under the skin.

For more information on relapse management, please visit MSAA’s MS Relapse Resource Center, found at relapses.mymsaa.org. Please also refer to MSAA’s MS Relapse Toolkit, with helpful tools for understanding MS relapses, learning about treatments, and preparing for these unexpected flare-ups in disease activity. Please visit mymsaa.org/publications/ms-relapse-toolkit/ to view or order a copy of this booklet.

The Importance of Long-Term Treatment

Since the 1990s, the FDA-approved disease-modifying therapies (DMTs) were only available for individuals with relapsing forms of multiple sclerosis – largely for those with RRMS. However, in early 2017, a new medication, Ocrevus™ (ocrelizumab), was approved for both relapsing forms of MS as well as primary-progressive MS, which was very exciting news for the MS community. Research continues at a rigorous pace to find additional treatments aimed at treating all forms of MS. In addition, symptom-management strategies and comprehensive care plans with teams of doctors, nurses, and therapists, help to greatly improve the quality of life for all individuals with MS – both with relapsing and progressive forms of MS.

Treatment with a long-term DMT is crucial for most people with relapsing and now progressive forms of MS, since disease activity and damage usually continue within the CNS even when no new symptoms are present. When a patient begins a treatment regimen early in his or her disease course, disease activity is slowed for most individuals. This not only reduces the number and severity of symptom flare-ups, but also reduces the number of active lesions that appear on an MRI, as well as delays the progression of the disease (possibly delaying any related disability).

An ongoing study with more than 20 years of data demonstrates that individuals with RRMS who began therapy early in the disease found that they experienced a longer lifespan than those who did not begin treatment as early. This study was conducted with a specific DMT; more studies are needed to see if the same is true for all DMTs.

Getting early treatment and staying on a DMT for MS may also delay the rate of conversion from RRMS to secondary-progressive MS (SPMS). This latter form of MS that follows RRMS exhibits a steady worsening, with or without relapses. If flare-ups do occur, they usually do not remit fully. As mentioned earlier, without treatment, about half of individuals with RRMS convert to SPMS within 10 years. However, since the introduction of the first treatment in 1993, those taking a DMT have reduced or delayed the conversion to SPMS.
The following chart includes the 16 disease-modifying therapies (DMTs) currently (at the time of printing) approved by the Food and Drug Administration (FDA) for the long-term treatment of MS. Additional DMTs are likely to be approved by the FDA in the near future. All of these DMTs are approved for treating either relapsing-remitting MS (RRMS) or all relapsing forms of MS, with the exception of Ocrevus™, which is also approved for primary-progressive MS (PPMS). Some have also been approved for “clinically isolated syndrome” (CIS), which refers to the initial symptom a patient reports prior to a diagnosis of MS.

As noted earlier, DMTs work to slow disease activity by reducing the number and severity of symptom flare-ups, reducing the number of active lesions that appear on an MRI, and potentially delaying the progression of the disease (possibly delaying any related disability). For more information on long-term treatments for MS, including any new approvals, please visit MSAA’s website at mymsaa.org to see the latest news, or call MSAA’s Helpline at (800) 532-7667, extension 154. Readers may also get information on how to select the most appropriate treatment through MSAA’s S.E.A.R.C.H.™ program at mymsaa.org/search.

### The following medications are given at one’s home via subcutaneous (under-the-skin) self-injection, with the exception of Avonex®, which is given via intramuscular (deeper in the tissue) self-injection:

<table>
<thead>
<tr>
<th>Medication</th>
<th>Administration</th>
<th>Assistance Programs</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Avonex®</strong></td>
<td>Given once weekly</td>
<td><em>Above MS</em> (800) 456-2255 / <a href="http://www.avonex.com">www.avonex.com</a></td>
</tr>
<tr>
<td><em>(interferon beta-1a)</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Betaseron®</strong></td>
<td>Given every other day</td>
<td><em>BetaPlus</em> (800) 788-1467 / <a href="http://www.betaseron.com">www.betaseron.com</a></td>
</tr>
<tr>
<td><em>(interferon beta-1b)</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Copaxone®</strong></td>
<td>Given daily or three-times weekly</td>
<td><em>Shared Solutions</em> (800) 887-8100 / <a href="http://www.copaxone.com">www.copaxone.com</a></td>
</tr>
<tr>
<td><em>(glatiramer acetate)</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Extavia®</strong></td>
<td>Given every other day</td>
<td><em>Patient Services Program</em> (866) 398-2842 / <a href="http://www.extavia.com">www.extavia.com</a></td>
</tr>
<tr>
<td><em>(interferon beta-1b)</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Glatopa®</strong></td>
<td>Given daily or three-times weekly</td>
<td><em>GlatopaCare</em> (855) 452-8672 / <a href="http://www.glatopa.com">www.glatopa.com</a></td>
</tr>
<tr>
<td><em>(glatiramer acetate)</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Generic Glatiramer Acetate Injection</strong> <em>(glatiramer acetate)</em></td>
<td>Given daily or three-times weekly</td>
<td><em>Mylan MS Advocate Program</em> (844) 695-2667 / <a href="http://www.glatirameracetate.com">www.glatirameracetate.com</a></td>
</tr>
<tr>
<td><strong>Plegridy®</strong></td>
<td>Given once every two weeks</td>
<td><em>Above MS</em> (800) 456-2255 / <a href="http://www.plegridy.com">www.plegridy.com</a></td>
</tr>
<tr>
<td><em>(peglinterferon beta-1a)</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Rebif®</strong></td>
<td>Given three-times weekly</td>
<td><em>MS Lifelines</em> (877) 447-3243 / <a href="http://www.rebif.com">www.rebif.com</a></td>
</tr>
<tr>
<td><em>(interferon beta-1a)</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Zinbryta®</strong></td>
<td>Given once per month</td>
<td><em>Above MS</em> (800) 456-2255 / <a href="http://www.zinbryta.com">www.zinbryta.com</a></td>
</tr>
<tr>
<td><em>(daclizumab)</em></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Given via intravenous (IV) infusion, usually at a hospital or infusion center:

<table>
<thead>
<tr>
<th>Medication</th>
<th>Administration</th>
<th>Assistance Programs</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Lemtrada®</strong> <em>(alemtuzumab)</em></td>
<td>Given for a course of five days, with a three-day course one year later</td>
<td><em>MS One to One</em> (855) 676-6326 / <a href="http://www.lemtrada.com">www.lemtrada.com</a></td>
</tr>
<tr>
<td><strong>Novantrone®</strong> <em>(mitoxantrone)</em></td>
<td>Given every three months; seldom prescribed due to serious health risks</td>
<td><em>N/A</em></td>
</tr>
<tr>
<td><strong>Ocrevus™</strong> <em>(ocrelizumab)</em></td>
<td>Given every six months, with the initial dose given in two half-doses</td>
<td><em>Genentech Access Solutions</em> (844) 627-3887 / <a href="http://www.Genentech-Access.com">www.Genentech-Access.com</a></td>
</tr>
<tr>
<td><strong>Tysabri®</strong> <em>(natalizumab)</em></td>
<td>Given every four weeks</td>
<td><em>Above MS</em> (800) 456-2255 / <a href="http://www.tysabri.com">www.tysabri.com</a></td>
</tr>
</tbody>
</table>

### Taken orally at one’s home:

<table>
<thead>
<tr>
<th>Medication</th>
<th>Administration</th>
<th>Assistance Programs</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Aubagio®</strong> <em>(teriflunomide)</em></td>
<td>One tablet taken daily</td>
<td><em>MS One to One</em> (855) 676-6326 / <a href="http://www.aubagio.com">www.aubagio.com</a></td>
</tr>
<tr>
<td><strong>Gilenya®</strong> <em>(fingolimod)</em></td>
<td>One capsule taken daily</td>
<td><em>Patient Services Program</em> (800) 445-3692 / <a href="http://www.gilenya.com">www.gilenya.com</a></td>
</tr>
<tr>
<td><strong>Tecfidera™</strong> <em>(dimethyl fumarate)</em></td>
<td>One tablet taken twice daily</td>
<td><em>Above MS</em> (800) 456-2255 / <a href="http://www.tecfidera.com">www.tecfidera.com</a></td>
</tr>
</tbody>
</table>

---

14 • THE FDA-APPROVED LONG-TERM TREATMENTS FOR MS

---

THE FDA-APPROVED LONG-TERM TREATMENTS FOR MS • 15
Multiple Sclerosis Symptoms

MS has the potential to cause several different symptoms and the specific symptoms each person experiences vary greatly. When experiencing one or more of these symptoms, individuals should consult their physician. Medications are available to treat many MS symptoms. These may include over-the-counter drugs as well as prescribed medications. Diet, exercise, counseling, and lifestyle/wellness therapies, may also be helpful with managing certain symptoms. All treatments are best accomplished through the guidance of a qualified healthcare professional.

MS symptoms are often compounded by extreme fatigue, which may be worse in the afternoon, sometimes relating to a rise in body temperature. Some symptoms may be temporarily increased by heat intolerance – a classic MS tendency, where a rise in temperature (internally or externally) causes a person to feel much worse. Keeping cool through air-conditioning or various cooling devices (such as those offered by MSAA’s Cooling Distribution Program), may be helpful for people with heat-sensitive MS.

When recovering from a symptom flare-up or learning to cope with a change in mobility, rehabilitation through physical therapy and occupational therapy can be of great value. Speech therapy, therapeutic exercise, and certain medical devices may also be useful in dealing with the symptoms of MS. Some of those who have a physically demanding or highly stressful job may choose to make a career change, in which case vocational training is helpful.

When a family member is diagnosed with MS, participating in some type of counseling program is often of benefit to everyone involved. Individuals may be affected in different ways, both physically and emotionally. Seeking professional assistance helps to ensure that MS does not disrupt one’s family and happiness.

A wide variety of symptoms can occur with MS. To help categorize the effects of MS, MSAA has listed the commonly experienced symptoms alphabetically in three groups, as follows:

Common Physical Symptoms of MS
- balance problems
- bladder dysfunction
- bowel problems
- muscle spasticity (stiffness)
- sexual dysfunction
- speech difficulties
- swallowing disorders
- tremor
- walking and mobility issues

Common Emotional, Mental, and Psychological Symptoms of MS
- anxiety
- cognitive changes
- depression
- Pseudobulbar Affect (PBA – a neurologic effect characterized by sudden, uncontrollable expressions of laughter or crying without an apparent trigger)
- weakness

Common “Invisible” Symptoms of MS
- dizziness/vertigo
- fatigue
- numbness
- pain
- sleep issues
- Uhthoff’s syndrome (the temporary appearance of symptoms resulting from heat stress)
- visual disorders

For more information on symptom management and handling the challenges of MS, please visit mymsaa.org/symptoms. MSAA offers several helpful publications and videos, as well as an extensive collection of MS-related books from MSAA’s Lending Library, which may all be found on MSAA’s website at mymsaa.org. Additionally, MSAA’s Client Services Specialists are available to discuss a caller’s needs and questions personally. To speak with a Specialist, please call (800) 532-7667, extension 154 or email MSquestions@mymsaa.org.
How MSAA Can Help

INFORMATION AND EDUCATION

MSAA’s website provides a wealth of information at mymsaa.org. This includes important news and timely updates, online videos, event listings, and more.

Multiple Sclerosis Information (MSi) is MSAA’s growing library of award-winning, on-demand video programming and archived webinars. These feature healthcare professionals who provide valuable insights and updated information on the latest advances in MS research, disease and symptom management, wellness strategies, and more. Please visit mymsaa.org/videos for more information.

All of MSAA’s award-winning publications are designed to be easy to read, informative, and inspiring. These include MSAA’s magazine, The Motivator, published twice yearly, and the widely acclaimed MS Research Update, published annually. Additional publications include Understanding Progression in MS, MS Relapse Toolkit, How to S.E.A.R.C.H.™ for the Right MS Therapy for You!, Aquatic Exercise and Multiple Sclerosis, and more. MSAA also offers two children’s books on MS. Please visit mymsaa.org/publications or call (800) 532-7667 for more information.

MSAA’s educational programs provide an excellent opportunity to connect clients with many of the country’s leading MS healthcare professionals. These events provide information in an easy-to-understand conversational format that strongly encourages open dialogue between clients and presenters. Please visit MSAA’s website (at mymsaa.org) and select “Educational Programs” from the “How MSAA Can Help” section to learn more.

TOLL-FREE HELPLINE AND OTHER SUPPORT

MSAA’s Helpline allows individuals with MS, family members, care partners, and friends, to speak directly with one of MSAA’s Client Services Specialists by calling (800) 532-7667, extension 154. MSAA’s Helpline hours are from 8:30 am to 5:00 pm Eastern Time on Monday, Tuesday, Thursday, and Friday; hours on Wednesday are extended from 8:30 am to 8:00 pm Eastern Time. Individuals may also email questions to MSquestions@mymsaa.org or have a live Chat at mymsaa.org/chat while visiting MSAA’s website.

MSAA’s Client Services Specialists offer encouragement to clients and their care partners to identify obstacles and discover ways to overcome them. Through MSAA’s Helpline, these Specialists may also recommend program(s) offered by MSAA as well as other resources that would be of help to the caller, and assist him or her with the application process. Members of the MS community are also encouraged to connect through MSAA’s blog, “MS Conversations” (located on MSAA’s website).

In addition, MSAA offers My MSAA Community, a free online community. For more information, please visit MSAA’s website and select the first entry below “Living with MS.” My MSAA Community is a peer-to-peer online forum (hosted by HealthUnlocked.com) for individuals with MS, their families, and their care partners to share information and their experiences with multiple sclerosis. Members of this friendly, supportive, and safe online community may connect with other people affected by MS, contribute to ongoing conversations, and start their own conversation with a question or a post about their journey.

SHARED-MANAGEMENT TOOLS TO MANAGE MS

“Shared Management” is a philosophy supported by MSAA, where both the patient and healthcare providers work together to achieve the best possible health outcomes for the patient. One example is MSAA’s S.E.A.R.C.H.™ Program, which provides tools to help individuals learn about approved long-term treatments for MS, along with questions to discuss with their medical team.

Another example is My MS Manager™ – MSAA’s mobile phone application. This app is provided free of charge to individuals with MS or their care partner to use on their iPhone, iPad, iPod touch, or Android mobile phone device. Developed in conjunction with @Point of Care, My MS Manager™ allows individuals to track disease activity, store medical information, and generate charts and reports on important details, such as symptoms and treatments.

Other HIPAA-compliant features with this app include optional private reminder settings, links to further educational materials from MSAA, and – exclusive to My MS Manager™ – the ability to connect to physicians and other clinicians on the healthcare team via the app to share progress and reports securely and as needed.
COOLING AND ASSISTIVE EQUIPMENT
MSAA provides equipment through both of the following programs at no charge and ships directly to clients. Please note that certain financial restrictions may apply.

**MSAA's Cooling Program** offers cooling vests and accessories for adults with multiple sclerosis as well as children diagnosed with pediatric MS. This technology helps many people with multiple sclerosis who are heat-sensitive, and who would otherwise experience increased symptoms when in warm temperatures. Please visit mymsaa.org/cooling for more information.

**MSAA's Equipment Distribution Program** offers products designed to improve safety, dignity, mobility, and independence. MSAA provides items such as shower chairs, grab bars, handrails, and mobility devices. Please visit mymsaa.org/equipment for more information.

**MRI ACCESS FUND**
MSAA's MRI Access Fund assists with the payment of cranial (brain) and c-spine magnetic resonance imaging (MRI) scans for qualified individuals who have no medical insurance or cannot afford their insurance costs. This fund is for individuals who require the exam to help determine a diagnosis of multiple sclerosis or evaluate current MS disease progression. Please visit mymsaa.org/mri for more information.

SUPPORTING MSAA
MSAA's programs and services are provided free of charge to members of the MS community (financial eligibility requirements apply for some programs). These programs are made possible through the support of our generous donors.

To support MSAA's vital programs and services, please visit MSAA's website at mymsaa.org. While there, visitors to our site may learn about several ways to make a donation – including donations made in honor or in memory of someone special. Website visitors may also find several options for participating in MSAA's fundraising initiatives, such as endurance events, golf tournaments, and Swim for MS. Individuals may also learn how to create their own event; examples include bake sales, bowling competitions, golf events, and more.

**Wellness Tips***

**Exercise**
Exercise is key in maintaining function in people with MS. In addition to showing positive effects on walking speed, endurance, and aerobic capacity in MS, exercise can also lower stress and improve mood, energy, physical health, and overall wellbeing. Aquatic exercise, yoga, and tai chi are among the many great exercise options that have positive effects for individuals with MS and may also be customized to suit one's preferences and ability levels.

**Diet**
Although no specific “MS diet” has been universally accepted by the medical community, food choices can make a difference in important issues such as energy level, bladder and bowel function, and overall health. MS specialists often recommend a low-fat, high-fiber diet, such as that recommended by the American Heart Association. Doctors agree that eating a healthy diet to promote general wellness and prevent certain other medical conditions could potentially have a positive impact on MS and its symptoms.

**Mind-Body Strategies**
**Mindfulness** has enormous potential for people with MS. The goal of mindfulness is to teach individuals to stay fully in the present, without added judgment or assumptions about their present or future situations. This technique has been shown to significantly decrease anxiety, depression, and stress in many conditions.

**Guided imagery** promotes biophysical and biochemical changes, bringing about benefits that range from improved mood, reduced depression, and lowered anxiety, to reductions in blood pressure and blood sugar, improved immune functions, and a reduction in pain. Guided imagery requires a state of deep relaxation, and adds the component of a gentle direction to encourage sensory images. A healthcare professional trained in guided imagery may use a script to first help the individual to relax, and then he or she may give a topic to imagine – such as a favorite place or an important goal. CDs, books, and other options are also available.

* Individuals should consult their physician prior to making any changes to their exercise routine or diet. Information shown originally appeared in MSAA's booklet, *Understanding Progression in MS* (2017).