

Veterans Affairs
Multiple Sclerosis
Centers of Excellence

Overview of Multiple Sclerosis for Veterans



U.S. Department
of Veterans Affairs

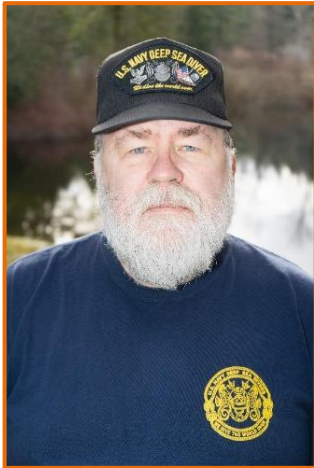
This booklet was developed and written by the **Veterans Affairs MS Centers of Excellence**. The Centers are dedicated to furthering our understanding of MS, its impact on Veterans, and effective treatments to help manage MS symptoms. Through partnerships with Veterans, caregivers, health care professionals, and MS advocacy groups the Centers hope to minimize disease impairment and improve health care services and quality of life for Veterans with MS.

In preparation of this MS booklet we thank our Veterans with MS who shared their stories and their journeys living with this disease, and for all the untold stories, we thank you. We thank the Veterans Service Organizations for their continued support and commitment to Veterans. We thank the MS associations for their dedication to provide education, support, and resources to people living with this disease. And lastly, we thank our Veteran's Health Administration health care colleagues who are committed to improving the lives of our Veterans.

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Veterans Living with MS



Dave « Navy

It was many years before I was diagnosed with MS. I was 48 and I went blind in my right eye. At the time, I thought I had a stroke, or worse. When I received the diagnosis of MS, I thought to myself, well this isn't so bad. I dove into learning more about the disease and started volunteering at my local VAMC, talking to other Veterans with MS

Jeanne « Air Force

In 1982 I started to have weakness and numbness in my right hand and constant bouts of what then was diagnosed as uveitis. The cause for this was "unknown diagnosis." After discharge from the Air Force, my symptoms, including numbness, falling, minimal loss of vision, and burning pain, mostly continued to haunt me. It wasn't until 1999 that I was diagnosed with MS.



Kim « Army

I was diagnosed with MS on February 25, 2003 while deployed for military duty. I thought my life as I knew it was going to change forever. I was right that my life did change, but not for the reason I thought. I did not know a lot about MS. I did not even realize that I had relatives with MS. For the past 11 years, I have come to the realization that "I am not my MS."

Introduction

As shared by these Veterans, it's common to experience a variety of symptoms before your multiple sclerosis (MS) diagnosis. Symptoms of MS often mimic those of other diseases. Ruling out other conditions is part of the diagnostic process. Sometimes this process is long or confusing. It's understandable if you may have felt worried or frustrated. Those who have served in the military are used to fixing problems, controlling situations, and supporting their comrades. Living well with MS will call on your skills and strengths in a new way. It's helpful to talk about your thoughts and feelings on dealing with the complexities of MS with your family and friends as well as your health care provider.

Along with the challenges of MS, there are many opportunities to take charge of your health and focus on what you CAN do. Developing strategies to help you adjust to living with a chronic health condition is key. Research shows that people living with a chronic illness, who take on self-management of their disease, have a higher quality of life and better outcomes. VA is here to help you develop those strategies.

VA is committed to supporting you to live a full and productive life, offering a complete spectrum of health care services. Your VA health care team will...

- help you understand MS,
- work with you to improve your overall health,
- explain your medication options for treating and managing MS,
- introduce you to specific strategies to help you manage your MS symptoms,
- support you and your family, and
- help you achieve your physical, psychological, vocational, and social goals.

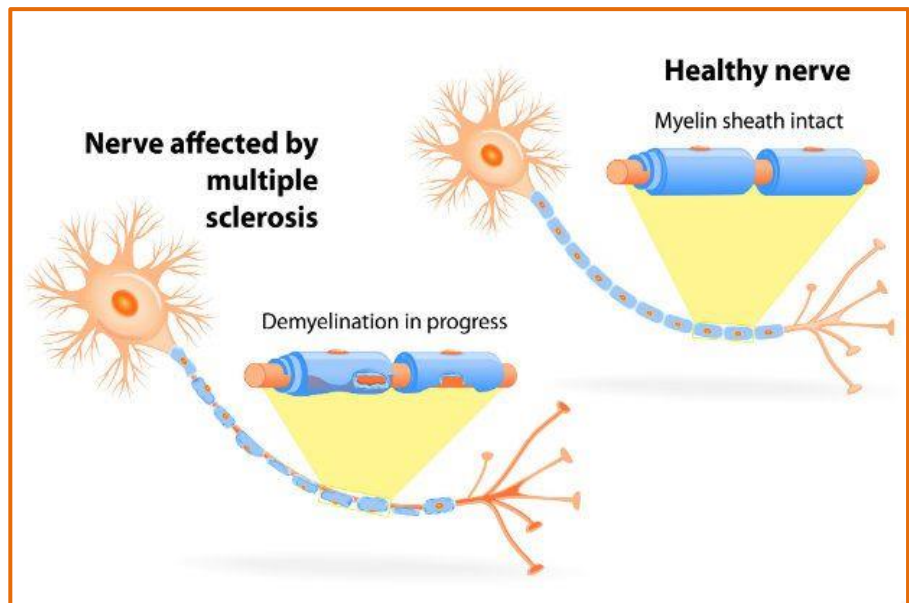
Your VA health care team will work with you and your family to develop an individualized plan for managing your health. We encourage you to learn as much as you can about MS and engage in your care. In this booklet we provide an overview of resources and strategies for living with MS.

Common Questions About MS

What is MS?

Multiple sclerosis (MS) is a complex neurologic disease that affects the central nervous system (CNS) - the brain, spinal cord, and vision pathways. In MS, the immune system attacks the myelin sheath, the fatty tissue that surrounds and protects nerve fibers, as well as the nerve fibers themselves. This damage is called demyelination and the scar tissues that develop when myelin is damaged are called scleroses, also known as lesions or plaques. Damage also occurs as unprotected nerves become fragmented and degenerate over time, also called neurodegeneration.

Whether damage occurs through demyelination or neurodegeneration, the nerve impulses traveling to and from the brain and spinal cord are distorted or interrupted, causing a wide variety of symptoms. Sometimes the myelin and nerves can repair themselves and the MS symptoms improve to a degree.



However, over time the myelin and underlying nerve fibers cannot recover and suffer permanent damage. This may lead to a gradual decline in function depending on the disease course. Several MS disease courses have been identified.

Relapsing-remitting MS (RRMS) is the most common MS disease course. About 85% of people with MS are first diagnosed with RRMS. RRMS is characterized by clearly defined relapses, followed by periods of partial or complete recovery, with no apparent progression of the disease in between relapses.

An MS relapse, also called an “attack,” “exacerbation”, or “flare,” is a rapid, significant worsening of existing symptoms or development of new symptoms, lasts at least 24

hours, and is not caused by infection, fever, or other stress. A relapse is significantly worse than mild, daily fluctuations in symptoms. It is caused by acute demyelination in the brain, spinal cord, or optic nerves. In contrast, a pseudo-relapse is an increase in MS symptoms due to infection, overheating, or excessive stress. There is no actual demyelination occurring during a pseudo-relapse.

People with **secondary-progressive MS (SPMS)** are initially diagnosed with RRMS and then transition to a more progressive form of the disease caused by neurodegeneration. This course is characterized by progression of disability over years, with fewer or no further relapses. Use of MS disease-modifying medications can delay the transition to SPMS. Not everyone with RRMS will transition to SPMS.

Primary progressive MS (PPMS) is characterized by progressive worsening of disease from onset without clear relapses. There may be changes in the rate of progression or periods of stability during the course of PPMS. About 15% of people with MS have this course.

Clinically isolated syndrome (CIS) is the diagnosis for those who have had only one episode typical of an MS relapse. People who experience a CIS are at higher risk of developing MS and are sometimes started on MS medications.

Radiologically isolated syndrome (RIS) is a term used for people who have a brain or spine magnetic resonance image (MRI) that looks typical for MS, but who do not have the clinical symptoms that meet diagnostic criteria for MS. MS cannot be diagnosed by an MRI alone.

What causes MS?

The cause of MS is currently unknown. What we do know suggests that there isn't one single reason why someone gets MS. Instead, there are probably a combination of different factors involved - both genetic and environmental.

Genetic Factors

Research into the genetics of MS has identified over 200 genetic variations that may play a role in raising the risk of MS. But not everyone who has these genetic variations will get MS. MS can occur more than once in a family, but this is not very common. The

risk of developing MS in the general populations is about 0.1-0.5% (1 in 1000 to 1 in 500 people) while the risk for a child with one parent or sibling who has MS is approximately 2-4% (1 in 50 to 1 in 25 people). For more distant relatives, the risk is about 1% (1 in 100 people). However, an identical twin of someone with MS has a 25-30% (1 in 3 people) chance of getting MS. This tells us that while there is a genetic element to getting MS, genetics is only part of the whole story.

Environmental Factors

A single environmental factor causing MS has not been identified. We know that MS is more common the further north or south a person lives from the equator during early life. This suggests there's something in the environment that plays a role in MS. There's increasing evidence showing that low levels of **vitamin D** - before birth or during childhood - may increase someone's chances of developing MS and the severity of MS. Vitamin D is produced by our skin when exposed to sunlight. People who live closer to the equator tend to have more exposure to the sun.

Research shows that common childhood viruses, such as the **Epstein Barr virus**, have a role to play in MS, but that role is not clear. Many people exposed to the same viruses do not have MS.

Smoking and passive smoke-exposure increase the risk of developing MS. People with MS who smoke are more likely to experience worsening of their MS symptoms, progress to secondary-progressive MS at a faster rate and have greater risk of

TAKE ACTION!

If you are a smoker, consider participating in the VA Tobacco Cessation Program. It's healthier for you, and for others, especially children in your home. (www.mentalhealth.va.gov/quit-tobacco | 855-QUIT-VET)

If you have extra weight, consider participating in the VA MOVE! Weight Management Program. MOVE! encourages healthy eating and increased physical activity. With the help of your MOVE! care team, you can reduce health risks from MS and many other diseases.

(www.move.va.gov)

increasing disability. It's not yet clear exactly why this is, although one theory is that the chemicals in tobacco smoke affect the immune system.

Obesity in early life has been identified as a predictor of MS risk. Obesity may also worsen the course of MS. Both may be true due to a general increase in the levels of inflammation in the body due to obesity.

While some neurological diseases, such as amyotrophic lateral sclerosis (ALS), have been associated with deployment in the military, this relationship has not been seen with MS.

What are the symptoms of MS?

MS symptoms vary depending on the location of the lesions in the brain and spinal cord. The duration and severity of symptoms may fluctuate over time. Most people do not have all the possible symptoms of MS, and no two people have the same combination or severity of symptoms.

Bladder dysfunction symptoms can include urgency or hesitancy in starting urination, increased frequency, incontinence (inability to hold urine), incomplete bladder emptying, involuntary leaking, and urinary tract infections.

Bowel dysfunction symptoms may include constipation, diarrhea, and fecal incontinence.

Cognitive dysfunction can affect memory, attention, information processing, verbal fluency, multi-tasking, and problem solving.

Depression symptoms may include feelings of low self-esteem, guilt or despair, a loss of interest in otherwise enjoyable activities, and disruptions in sleeping or eating. Talk to your health care provider if you experience any of these symptoms longer than two weeks.

Dizziness or **vertigo** (sensation of spinning) may give the sensation that you or your surroundings are spinning or off-balance.

Dysphagia symptoms can include coughing, choking on food or drink, difficulty swallowing solids or liquids, difficulty chewing, a feeling of food "stuck" in the throat, choking on saliva, or drooling.

Emotional variability (moodiness) symptoms involve rapid and random changes in emotions, with frequent bouts of anger or irritability. Uncontrollable and often random episodes of laughing and/or crying may be due to **pseudobulbar affect** (PBA). PBA episodes have little or no relationship to events or the person's real emotions.

Fatigue in MS is often described as an overwhelming sense of tiredness, lack of energy, or a feeling of exhaustion that is not caused by activity and is often unrelieved by rest.

Gait (walking) problems are related to issues with balance, strength, sensation, and coordination.

Hearing loss signs can include difficulty understanding words or following a conversation involving more than two people, ringing in the ears, sounds seeming muffled, or needing a higher volume on electronic devices.

Heat sensitivity can cause MS symptoms to temporarily worsen in hot weather, with fevers after strenuous exercise or during a hot bath or shower.

Numbness or **tingling** sensations can be mild or severe, may vary from continuous to intermittent, and can occur in the face, body, or extremities.

Pain that is **neurogenic** or **neuropathic** is directly related to an MS lesion in the CNS. It is often described as burning, stabbing, tingling, or like an electric shock.

Musculoskeletal pain is often the result of living with disability. Muscles, bones, or joints can be painful when stressed due to decreased mobility, long sitting, spasms, and improper use and disuse of these body parts.

Respiration problems can include increased effort in breathing (inhaling and exhaling), interference with speech or voice loudness, as well as difficulty sleeping.

Seizures occur in about 5% of people with MS. These are due to MS lesions in areas of the brain that are also prone to develop seizures. Seizures are treated with anti-epileptic medications.

Sexual dysfunction symptoms include loss of libido, reduced genital sensation, failure to achieve orgasm, erectile dysfunction, decreased vaginal lubrication, and changes in arousal and response.

Spasticity (muscle stiffness) is described as tightness, pulling, tugging, aching, and stiffness. Spasticity can occur throughout the body and can limit mobility, require excessive effort, and cause discomfort.

Speech dysfunction includes slurred speech, low volume or weak voice, changes in resonance and pitch control, difficulty with word finding, and pauses between words or syllables of words.

Tremors are involuntary shaking or trembling of a limb, muscle, or occasionally the head.

Vision problems are often the first MS symptoms. **Optic neuritis** is inflammation of the optic nerve that causes a temporary partial or complete loss of vision or change in color perception. **Double vision** occurs when the muscles coordinating eye movements are weak. **Nystagmus** is uncontrolled jerky eye movements which may impair vision.

Weakness commonly affects the muscles involved in walking but may also affect the upper body.

Managing MS symptoms requires a team approach. Your MS provider will call upon a wide range of helpers to manage your MS symptoms starting with you and your family. Many MS symptoms are very responsive to self-care lifestyle changes such as exercise, good nutrition, healthy sleep habits, and positive social relationships. Medications, physical and occupational therapies, and other interventions are also available to help manage MS symptoms. Your MS provider will lead your MS Multidisciplinary Health Care Team to optimize your independent living with MS.

What treatment options are there for MS?

The goals for MS care are to reduce the frequency of relapses, slow the progression of the disease, manage symptoms, and improve quality of life. People with MS should work with their MS Multidisciplinary Health Care Team to find the best approach to managing their MS.

Lifestyle Management

MS management starts with a healthy approach to self-care. This includes regular exercise, a healthy diet, restorative sleep, and strong relationships. Research shows that following a healthy lifestyle can result in better MS outcomes, delay disability, and maintain independence.

Disease Modifying Therapies

Many US Food and Drug Administration (FDA)-approved disease modifying therapies (DMTs) are available for the treatment of MS. These DMTs reduce the number of MS relapses and delay neurologic disability. Be aware that DMTs do not treat chronic symptoms or restore lost function. Most DMTs work best in people who have a relapsing form of MS. Development of DMTs for people with progressive MS (both PPMS and SPMS) is an area of active research.

People with MS who are good candidates for a DMT should start treatment as soon as possible. [Research shows that early treatment with a DMT can reduce long-term disability from MS.](#) Use of DMTs is not limited by the frequency of relapses, age, or level of disability, although these are all considerations in DMT choice. Treatment continues until it is clearly no longer effective, there are intolerable side effects, or a better treatment becomes available. DMT information and options are available on the VA website www.va.gov/MS as well as the National MS Society website www.nationalmssociety.org. As with all medications, there can be side effects. Your MS provider will discuss these with you and help you to select the most appropriate medication. If your condition changes or you experience bothersome medication side effects, your VA health care team will work with you to find solutions.

Symptomatic Therapies

There are many useful approaches to managing the symptoms of MS - such as physical therapy for muscle stiffness, occupational therapy for tremor, a cooling vest for heat sensitivity, speech therapy for swallowing and cognitive issues, Botox for urinary incontinence, and more. The treatment approaches may not always make the symptom go

PRO TIP

- Discuss your MS disease course with your health care provider as well as the benefits and risks of therapies.
- Contemplate the route of the therapy - oral, self-injection by needle, or clinic appointment infusion (into the vein) - and your ability to take the therapy as prescribed.
- Understand how often you'll need to be seen for exams, labs, infusions, and follow-up care.
- Consider your overall health and family planning.

away completely, though they can often make them easier to manage. If the first treatment doesn't work or has too many side effects, there are others you can try. It may be important to address the most bothersome symptom first. Discuss your options with your MS health care team. They will work with you to create an individualized treatment plan and add the right members to your MS Multidisciplinary Health Care Team.

Relapse Management

Mild relapses which do not impair function don't need treatment, however more severe relapses are usually treated with steroid medications. Treatment speeds recovery from a relapse but will not affect how well a person recovers. You and your MS Multidisciplinary Health Care Team should make the decision together whether steroids are a good option for you. During and after a relapse, you may need to work with a rehabilitation therapist to help with any changes to your ability to perform activities of daily living. If you think you may be experiencing a relapse, contact your MS provider right away.

Complementary Therapies & Integrative Medicine

Included in complementary therapies are products and practices that are not currently part of "mainstream" medicine, although what is considered mainstream varies by community and over time. These approaches include nutritional supplements, stress reduction techniques, mindfulness meditation, physical programs like yoga or chiropractic manipulation, acupuncture, and others. VA continues to research the safety and effectiveness of complementary and integrative therapies for MS. VA supports the use of appropriate integrative medicine, which combines the practices of complementary therapies and standard care. Always check with your MS provider before trying complementary therapy; some may not be helpful for people with MS or may have side effects and interactions with other medicines that need monitoring.

What can I expect in the future?

MS is an unpredictable disease and no two people are affected by MS in the exact same way. Relapses can't be predicted, and progressive disease may stabilize or

worsen unexpectedly. People that experience chronic MS symptoms may find that their symptoms change from day to day, even hour to hour. Changes may be related to fatigue, stress, illness, menstrual periods, or increased body temperature. Others report changes for no obvious reason at all. Some people have no MS symptoms from day to day.

The unpredictable nature of MS relapses, symptom changes, and the challenges associated with planning for the future may be some of the hardest parts of living with MS. It can take some time to come to terms with it all. There is support available at your local VA and with community support groups.

Mobility

Many people with MS worry that their mobility will be impacted by MS. However, not everyone with MS will need a wheelchair. If you're recently diagnosed with MS, it's likely too soon to make predictions about whether you may need any adaptive mobility aids in the future. People with severe fatigue, weakness, balance problems, or spasticity that interfere with walking safely may benefit from walking aids such as canes, walkers, scooters, and wheelchairs. These people find that with adaptive aids they are not only safer, but they move faster and with less effort, and can enjoy various activities again.

Employment

Being told you have MS can make the future seem uncertain. It's natural to worry about what this means on your job, home, and finances. It's important not to rush into any major decisions. Although some people might find their MS symptoms affect their ability to put in the same hours or do the exact work they had been doing, many people are able to continue working. VA has therapists, services, and adaptive technology options to help with decisions about work and your work environment. The Americans with Disabilities Act provides standards to help you and your employer find reasonable accommodations to help keep you working. (www.ADA.gov)

Family Planning

Having MS doesn't affect a man or woman's fertility. Large studies have shown that MS does not affect pregnancy, labor, or delivery of a child. In fact, pregnant women have fewer MS relapses, especially in the second and third trimesters. Because relapse rates

can increase 20-40% in the first 3-6 months postpartum, it is important to be in close contact with your MS provider during and after pregnancy and deliveries.

DMTs taken by mothers and fathers before conception and by mothers during pregnancies present various levels of risk to the developing fetus. There are more decisions to be made around breastfeeding. We encourage you to work with your MS provider and obstetrician to discuss MS management along with family planning and contraception to ensure a safe and healthy pregnancy and baby.

Should I tell others about my MS?

Sharing your diagnosis of MS to friends, colleagues, or your employer is a complex, personal decision. Individual relationships are different and how much you share with one person may not be the same for another. There may be advantages to not disclosing your medical diagnosis. It's important that you take time to consider this decision since once you've disclosed your MS diagnosis to someone, it can't be undone.

Sharing your diagnosis of MS to those closest to you can be a good way to get the support you may need as well as assist you in the coping process. Disclosure of your diagnosis in the workplace could have significant immediate or future impacts and should be carefully considered. There is no rule that you must share your diagnosis with an employer. Under the Americans with Disabilities Act, employers only need to know if you can do your job, and if reasonable accommodations are needed to help you carry out your job.

PRO TIP

If you have questions or concerns regarding disclosure and would like to better understand the pros and cons for you, talk to your VA health care provider. VA has psychologists, vocational rehabilitation counselors, social workers, and therapists who can help you better understand this decision. You can also learn about your rights in the workplace at www.ADA.gov.

Multidisciplinary Health Care Team

VA has a large network of health care professionals who are available to help you with your care, keeping care as close to your home as is possible. Knowing who will be involved with your care is important. The members of your MS Multidisciplinary Health Care Team will work with you to ensure you get the care you need, when you need it.

As the person with MS, **YOU** will get to know more about your condition than anybody else. You understand how your symptoms affect you, both physically and mentally. You can monitor any changes in your condition and learn what triggers to avoid that may make your symptoms worse. Remember, too, that having the right information about MS will mean you'll be in a better position to make informed decisions for yourself. The more you know, the more you can help your MS Multidisciplinary Health Care Team help you.

Neurologists are physicians that specialize in the treatment of disorders that affect the brain, spinal cord, and nerves. They provide testing and assessment for the diagnosis of MS as well as ongoing care and management for symptoms and disease activity or progression.

Physiatrists (Physical Medicine and Rehabilitation physicians) manage symptoms that limit function in day-to-day life or your ability to participate in work and the community. Your rehabilitation provider may be involved with your care for a specific issue, or for long-term management of your MS.

Primary care physicians focus on preventive health and chronic disease management. They coordinate care with other specialty care providers and programs and can manage some chronic MS symptoms without the help of MS specialists.

Nurse practitioners and **physician assistants** provide a wide range of health care services including establishing plans of care, diagnosis, medication management, addressing complex medical issues, education, training, and collaborating with other specialties.

Nurses provide direct care to Veterans in addition to coordinating services, promoting health and wellness, and providing advice and education about your specific symptoms and various health conditions.

Psychologists assist Veterans with mental, emotional, or behavior challenges, evaluate psychological testing to identify cognitive strengths and weaknesses, and provide clinical and counseling services.

Social workers assist Veterans and their families in resolving emotional, psychosocial, and economic problems. Assistance includes counseling, providing information about VA and community resources, and planning for care after a Veteran leaves the medical facility.

Physical therapists assist Veterans with injuries and disabilities to improve their movement, restore function, reduce and manage their pain, and help with the appropriate selection for adaptive mobility devices.

Occupational therapists assist Veterans in developing, recovering, and improving the skills needed for activities that occur in daily life. They also help with energy conservation for fatigue and with the selection and use of assistive technology.

Speech therapists assist Veterans with speech, language, swallowing, and voice issues involving communication. They can provide evaluation and treatment options if needed.

Recreational therapists assist Veterans to engage in recreation-based treatment programs, which can include arts and crafts, sports, and community outings, to help maintain or improve Veterans' physical, social, and emotional well-being.

Depending on your symptoms, your MS Multidisciplinary Health Care Team may include health care providers in **Urology, Psychiatry, Sleep Medicine, Orthopedics, Nutrition, Gastroenterology, Pulmonology, Optometry**, and other medical specialties to help manage your MS.

Your primary care provider focuses on your general health concerns and will coordinate with your MS provider to address your chronic MS symptoms. Your MS Multidisciplinary Health Care Team can help you manage relapses or other challenging MS symptoms.

PRO TIP

Write down issues you would like to discuss with your MS provider before your appointment occurs. Be prepared to talk about your VA and non-VA medications, MS symptoms frequency and severity, mobility, mental well-being, sleeping patterns, and activities of daily living.

Lifelong Care & Services

All enrolled Veterans have access to VA's comprehensive medical benefits, but certain benefits will vary from person to person, depending on each Veteran's unique eligibility status. Once you are enrolled and your eligibility is verified, Veterans could be classified as service-connected or nonservice-connected.

Service-connected status refers to Veterans who are disabled by an injury or disease that was incurred or aggravated during active military service. If you had symptoms of MS while in the military or within 7 years after honorable discharge, you may be eligible for service-connected disability compensation, benefits, and extended services.

Nonservice-connected status refers to Veterans who have a disability or health issue that is not related to their military service. To determine your eligibility for service-connected or nonservice-connected disability status you need to apply for disability compensation (www.va.gov/disability). Additional information on benefits can be found at the Veterans Benefits Administration homepage www.benefits.va.gov or you can call 800-827-1000.

The list below identifies some of the many services that may be available to you as a Veteran. For more information visit the Veterans Benefits Administration website or talk to a member of your VA health care team.

VA Medical Services

- Imaging Services
- Mental Health Services
- Neurology Services
- Pain Management Services
- Prescription Services
- Preventative Care
- Primary Care Services
- Rehabilitation Services
- Smoking Cessation Services
- Spinal Cord Injury Services
- Substance Abuse Disorder Services
- Vision Services
- Women's Health Services

Home & Community Care

- Home Health Aides
- Home Modifications
- Hospice Care
- Independent Living Programs
- Long-Term Care Centers
- Respite Care
- State Veterans Home

Rehabilitative Care Programs & Therapies

- Adaptive Home Improvements
- Recreational Therapy
- Adaptive Medical Devices
- Respiratory Therapy
- Adaptive Medical Equipment
- Speech and Swallowing Therapy
- Driver Training Services
- Vehicle Modifications
- Occupational Therapy
- Vocational Rehabilitation Program
- Physical Therapy

Psychosocial Care & Services

- Caregiver Services
- Chaplain Services
- Fisher House Program (caregivers)
- Peer Activities and Counseling
- Post-Traumatic Stress Disorder Care
- Psychology Services
- Social Work Services

Prosthetic & Sensory Aids Service

As a Veteran with MS you are eligible for many services from the Prosthetic and Sensory Aids Service (PSAS) program. PSAS is an integrated delivery system designed to provide eligible Veterans with medical devices such as hearing aids, eyeglasses, speech and communication devices, orthopedic braces, supports, footwear, wheelchairs, scooters, home respiratory aids, hospital beds, and other daily-living aids. The basic eligibility for prosthetic items is enrollment in the VA system, proper medical justification, and an order from your health care provider. Service connection does not have a role in eligibility for most programs.

Community Care

Veterans may be eligible to receive care from a community health care provider when VA cannot provide the care needed. This care is provided on behalf of and paid for by VA. Community care is available to Veterans based on certain conditions and eligibility requirements, and in consideration of a Veteran's specific needs and circumstances. Community care must be first authorized by VA before a Veteran can receive care from a community health care provider. (www.va.gov/communitycare)

TAKE ACTION!

The VA has several services to support your family member who will have a role in your care. There are caregiver programs available both in and out of your home to help care for you as the Veteran, and for support of your family caregiver. Contact your local VA Social Work department for more information or call the VA Caregiver Support Line at 855-260-3274.

Self-Management for Living Well

An MS diagnosis may feel overwhelming, especially at first. People newly diagnosed with MS and their family members can experience a variety of emotions and reactions. There's no right or wrong way to react to a diagnosis of MS. You may even find that your reaction varies from day to day, perhaps changing from fear to anger to sadness, to relief. This is also normal. Many people with MS compare their emotional reaction to a rollercoaster ride, with its many ups and downs.

You will have a team of health care providers who will be partnering with you to help you live well with MS. The treatments prescribed by your MS Multidisciplinary Health Care Team are one part of managing your MS; your self-management is also important.

Realism and **flexibility** can help you make the most of living with MS. Every person's experience with MS is different. While MS might redefine some of your life's goals and objectives you will still have opportunities to "redefine your life's mission".

Finding good information about MS puts you in a better position to make informed decisions. There's so much MS information around, particularly on the internet, that it can be hard to know where to start. The information you read should be accurate, unbiased, and up to date, so you can use it to make the right choices. Be wary of anything that claims to be a miracle cure. Some companies try to profit on chronic conditions like MS by trying to sell unproven supplements, therapies, products, and equipment.

You can get reliable information on managing MS from your VA health care team, the VA MS Centers of Excellence website, the National Institutes of Health, reputable medical centers like the Mayo Clinic and Cleveland Clinic, and from recognized and respected MS not-for-profit organizations like the National MS Society, MS Association of America, and MS Foundation. A resource list is provided in the back of this booklet. If you have a smartphone, you can download VA apps from www.mobile.va.gov. These apps offer safe and secure mobile access to a variety of topics like mindfulness, mental health, and quitting smoking.

Setting goals can help point you in the direction you want to go and may provide a feeling of accomplishment. Involve your family and friends in goal setting. Setting goals together is an important part of life's journey. Your VA health care providers will ask

for your goals, they are essential to your care plan.

Eating well is helpful for everyone. Following a healthy, low fat diet, such as the one recommended by the American Heart Association (that recommends more vegetables and fruits), can improve your general health. You may also find you have more energy. It may also help you maintain a healthy weight or reduce extra weight that can increase strain on joints and limit mobility.

For more information about healthy food choices you can visit the VA Nutrition and Food Services website at www.nutrition.va.gov or the US Department of Agriculture website at www.choosemyplate.gov. Also, talk with your VA health care provider about a referral to a nutritionist.

PRO TIP

It's best to get your nutrients from food, yet sometimes vitamin or mineral supplements may be a good idea. Getting enough vitamin D is important for MS but can be hard to obtain through foods alone. Talk with your MS provider about getting your vitamin D level checked, and about whether you should add a supplement.

Communicate often and openly with your health care team and your family and friends. Talking about your needs as well as changes you are experiencing is important.

Supportive networks have helped thousands of people living with MS. Sharing experiences and advice, plus emotional and moral support can make a big difference. Support groups bring together people facing similar issues, allowing attendees to share experiences and advice, as well as offer emotional and moral support. VA and outside MS organizations have a variety of support programs for you and your family. The National MS Society's MS Navigators can help you find an MS support program near you. Call 800-344-4867 or send an email to contactusnmss@nmss.org to connect with a MS Navigator.

Primary care and specialty care **evaluations** should take place regularly. Primary Care providers and MS providers work closely to provide comprehensive care.

Stress is not uncommon. It is important to learn to manage your stress because

prolonged stress can be linked to headaches, upset stomach, trouble sleeping, a weakened immune system, or it might make a current health condition worse. VA offers a variety of programs to help manage personal stress with programs for your family members too.

Exercise increases a feeling of well-being and helps reduce fatigue, regulate sleep patterns, and manage appetite and bowel and bladder function. An exercise program can help reduce your risk of falling and maximize safety by strengthening your muscles and helping with balance. It may also reduce your risk of cognitive loss. Exercise can also help minimize risks from cardiac disease, diabetes, and other conditions that affect people with and without MS.

Being active involves finding the right activities to suit you and your abilities, as well as finding something that you enjoy. Swimming, yoga, bicycling, and Tai Chi are just some of the many helpful exercise options. Your VA's physical and recreational therapists can help you develop a personalized exercise plan, and can help you get the right gear for sports, help you train, and help if you need adaptations now or in the future.

TAKE ACTION!

Ask your VA health care provider about VA's special MOVE! Program (www.move.va.gov). MOVE! is available at all VA medical facilities. It is designed to improve the lives of Veterans by encouraging healthy eating behavior, increasing physical activity, and promoting weight loss to reduce health risks, prevent or reverse certain diseases, and improve quality-of-life and longevity.

Build **relaxation** into your schedule. VA has a variety of programs that enhance physical and mental relaxation, such as mindfulness or meditation yoga. Other techniques, such as deep breathing and progressive relaxation, may be learned from your VA therapists.

Keep a symptom journal to collect data on symptoms you are experiencing. Write down when you have them, how bad they are, and how long they last, as well as any triggers. This will help you and your health care team better understand your MS, recognize patterns, and plan your individualized treatment. You can use paper notebooks or try some of the high-tech tools and apps VA offers to support this effort.

Take advantage of resources and programs provided by government, Veteran Service, and not-for-profit MS organizations. There is a wealth of opportunities to learn more about MS and get engaged with others living with MS. Below is a list of organizations that the VA MS Centers of Excellence collaborate with, though there are many more.

- Disabled American Veterans (www.dav.org)
- MS Association of America (www.mymsaa.org)
- MS Foundation (www.msfocus.org)
- MSWorld.org (www.msworld.org)
- National Institute of Health Clinical Trials (www.clinicaltrials.gov)
- National MS Society (www.nationalmssociety.org)
- Paralyzed Veterans of America (www.pva.org)
- United Spinal Association (www.unitedspinal.org)
- US Department of Veterans Affairs (www.va.gov or www.vets.gov)
- VA MS Centers of Excellence (www.va.gov/ms)
- US National Library of Medicine: MedlinePlus (www.medlineplus.gov)
- VA My HealtheVet (www.myhealth.va.gov)
- VA National Center for Health Promotion and Disease Prevention (www.prevention.va.gov)
- VA Whole Health (www.va.gov/wholehealth)
- Veterans Health Library (www.veteranshealthlibrary.org)

Veterans Living with MS



Michael « Navy

I discovered adaptive sports through the VA; riding a bike, golfing, air gun shooting, and sailing were now things that I could do again. I even took some cooking classes at my local VA. In September 2019 I attended the National Disabled Veterans Tee-Tournament in Iowa City, IA with about 400 other Veterans. It was amazing to see so many Veterans together, competing in sports and making the most out of life.

Suzanne « Navy

I find such joy in being around others who understand me and am so proud of all the projects I've been able to be a part of. I've found that the secret to living with MS is not just staying active but getting out of your comfort zone and pushing yourself to do new things and meet new people.



Nick « Army

Having a strong support team makes the hurdles much easier to jump through. My support includes family, friends, and people I've met at MS events and support programs. I found a wealth of information and advice from people through meeting others affected by MS who have similar experiences and issues to mine

This MS booklet is brought to you by the US Department of
Veterans Affairs Multiple Sclerosis Centers of Excellence.

For more information on MS and VA services please contact us
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U.S. Department of Veterans Affairs

Veterans Health Administration
Multiple Sclerosis Centers of Excellence

version 06/2021
IB 10-977