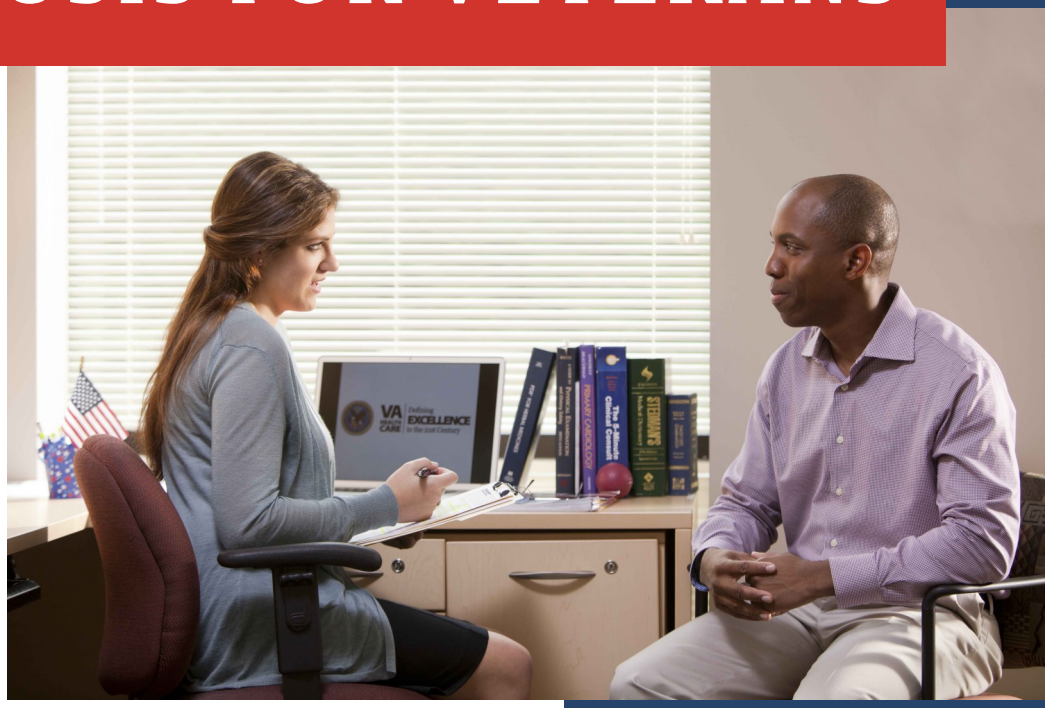
Veterans Affairs
Multiple Sclerosis
Centers of Excellence

OVERVIEW OF MULTIPLE SCLEROSIS FOR VETERANS



U.S. Department of Veterans Affairs

ACKNOWLEDGEMENTS

In preparation of this multiple sclerosis booklet we thank our Veterans with MS who shared their stories and their journeys living with this disease, and for all of the untold stories, we thank you.

We thank the Veterans Service Organizations for their continued support and commitment to Veterans.

We thank the multiple sclerosis 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

REX ★ ARMY

Some days my legs would tingle or I'd feel a little dizzy; other days I'd feel fine. It was difficult to get a full understanding of what was going on since I was never in one place long enough. I was soon led down a path of medical procedures which ruled out what I didn't have, but failed to tell me what I did have. In 1987, a neurologist noticed a pattern in my symptoms and sent me for an MRI. The MRI showed that I had MS, something that was never mentioned in any of my previous medical procedures.

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 actual multiple sclerosis (MS) diagnosis. Symptoms of MS often mimic those of other diseases. Ruling out any other condition 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 complexity 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 is here to…

- 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.

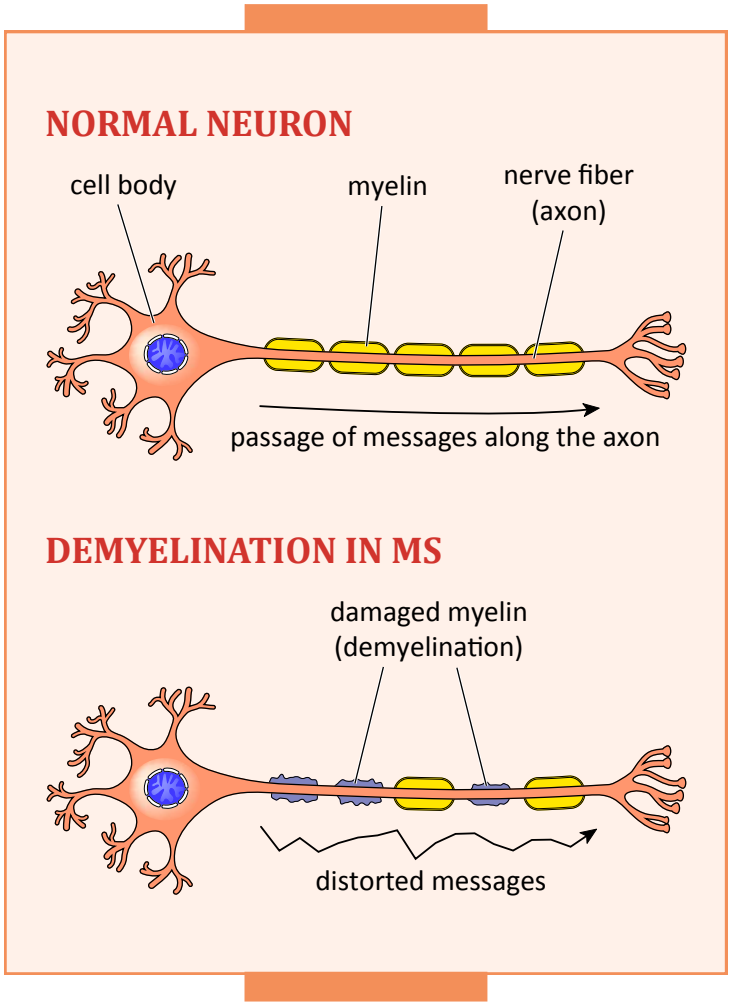
Your VA health care team will work with you and your family to develop an individualized plan for managing your health. We encourage you to learn as much as you can about MS and engage in your care. In this booklet we provide an overview of resources and strategies for living with MS.

COMMON QUESTIONS ABOUT MS

WHAT IS MS?

Multiple sclerosis (MS) is a complex neurologic disease that affects the central nervous system (CNS) which includes 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 **sclerosis**, also known as lesions or plaques.

When any part of the myelin sheath or nerve fiber is damaged or destroyed, nerve impulses traveling to and from the brain and spinal cord are distorted or interrupted, causing a wide variety of symptoms. Sometimes the myelin can repair itself and the MS symptoms go away after the immune attack, or relapse. 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 this course. It is characterized by clearly defined relapses. These relapses are followed by periods of partial or complete recovery with no apparent progression of the disease 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 which can be commonly experienced. It is caused by acute demyelination in the brain or spinal cord.

A **pseudo-relapse** is a significant increase in symptoms due to infection, overheating, or excessive stress. There is no actual demyelination occurring during a pseudo-relapse.

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 the disease. About 15% of people with MS are first diagnosed with this course.

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

Clinically isolated syndrome (CIS) is a term that describes symptoms similar to a typical MS relapse in a person not previously diagnosed with MS. People who experience a CIS are at higher risk of developing MS.

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 number of different reasons, or factors involved - both genetic and environmental.

Genetic Factors

There is a genetic link to MS, but it is not directly inherited like some other conditions. It isn't caused by one faulty gene. Research into the genetics of MS has identified over 100 genetic variations that may play a role in 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

JEFF ★ ARMY

I've had MS for over five years now and although I've had to make adjustments to accommodate some of my symptoms, life is good. I like keeping my body healthy, active, and fit. I enjoy life and every new day gives me an opportunity to get out there, meet new people, have new experiences, and raise awareness for MS.

common. A parent, sibling, or child of someone with MS has a 1-4% chance of having MS. More distant relatives have a risk closer to that of the general population, which is 0.1-0.5% (1-2 people per one thousand people). While there is a genetic element to MS, by no means is it the whole story.

Environmental Factors

A single environmental factor has not been identified. We know that MS is more common the further you are from the equator. This suggests there's something in the environment that plays a role in MS.

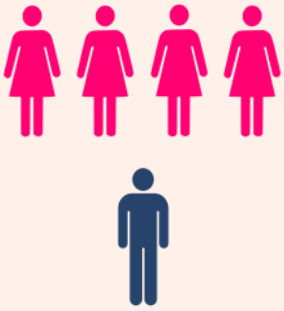
There's increasing evidence showing that low levels of **vitamin D** - before birth or during childhood - may increase someone's chances of developing MS. Vitamin D is produced by our skin when exposed to sunlight. People who live closer to the equator tend to have more exposure to the sun.

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 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. If you are a smoker, consider participating in the VA smoking cessation program. It's healthier for you, and for others, especially children in your home. (*www.publichealth.va.gov/smoking* | 855-QUIT-VET)

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.

About 4 women have MS for every 1 man who has 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 of 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 professional 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 problems (walking) 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.

DAWN ★ ARMY

I've had MS for over 34 years, experiencing my first MS exacerbation when I was 18 years old. My MS is unpredictable, but so is life. Some days are good, while other days are a little less good. Over the years, I've learned that I can't control everything that happens in life, but I can control how I react to life's unexpected changes and challenges. I can choose to find the good instead of focusing on the bad.

IVAN ★ COAST GUARD

We absolutely do not know what is next in life so we need to make the most of our abilities and time. There is no secret or miraculous cure just around the corner… My prescription for MS is to spend a lot of time with kids and animals and get plenty of sleep, fresh air, and sun. Avoid stress and stressful people. Actively manage your medications by eliminating those that don't help. Look out for the people you love by not expecting too much of them or letting them expect too much of themselves.

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 central nervous system. 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 problem symptoms can include increased effort in breathing (inhaling and exhaling), interference with speech or voice loudness, as well as difficulty sleeping.

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.

There are ways to manage any MS symptom. Many symptoms are very responsive to self-care lifestyle changes such as increased activity. Physical activity is helpful for anyone with MS, just as it is for the general population. Fatigue, insomnia, mood, cognition, mobility, spasticity, and bowel function may all be improved through regular physical activity. In addition, medications, therapies, and other interventions are available to help manage MS symptoms.

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. Medications for MS focus on controlling the immune system and managing symptoms. People with MS should work with their **MS Multidisciplinary Care Team** to find the best approach to addressing their MS symptoms.

Disease Modifying Therapies

Several US Food and Drug Administration (FDA) approved disease modifying therapies (DMTs) are available for the treatment of MS. These DMTs have been shown to reduce relapses and neurologic disability. Be aware that DMTs do not treat chronic symptoms or restore lost function.

People with MS who are good candidates for a DMT should start treatment as soon as possible. Research shows that early treatment with DMTs can reduce long-term disability from MS. Use of DMTs is not limited by the frequency of relapses, age, or level of disability. Treatment is not stopped unless it is it clearly no longer effective, there are intolerable side effects, or a better treatment becomes available. DMT information and options are available at *www.va.gov/MS*.

CHOOSING THE BEST DMT FOR YOU

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

As with all medications, there can be side effects. Your health care 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 a number of medications and other medical or interventional approaches that are useful to manage symptoms - such as physical therapy for muscle stiffness, occupational therapy for tremor, or a cooling vest for heat sensitivity. The treatment approaches may not always make the symptom go 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 health care provider and team. They will work with you to create an individualized treatment plan.

Relapse Management

Steroid medications may help speed up recovery from a relapse, though milder relapses may not require steroids. You and your 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 specialist right away.

Complementary Therapies & Integrative Medicine

The term "complementary and alternative medicine" (CAM) generally refers to products and practices that are not currently part of "mainstream" medicine. Complementary medicine is used with standard care, whereas alternative medicine is used instead of standard care. The term "integrative medicine" refers to care that blends both mainstream and complementary practices.

Some CAM approaches include nutritional supplements, lifestyle changes like stress reduction techniques, mindfulness meditation, physical programs like yoga or chiropractic manipulation, and pain management. VA continues to research the safety and effectiveness of CAM therapies for MS. VA supports the use of appropriate integrative medicine, which combines the practices of complementary and standard care. Always check with your health care provider before trying complementary therapy; some may not be helpful for people with MS or can make the symptoms of MS worse.

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. They do tend to affect the same body areas and involve the same symptoms as in

previous relapses, but new symptoms are possible. 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 unpredictability of 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. Individuals 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 individuals 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 to work. VA

PHILIP ★ AIR FORCE

What can life with MS look like? It looks like a man who was Area Captain for four states. It looks like a man, for the second time, who donned a tuxedo to attend the inaugural balls for the nation's re-elected first black president. It looks like a man sitting proudly at the inaugural ceremony. It looks like a man who mentors through the Boys and Girls Club, who reads at Lexington Elementary School, and who recruits through Team 100. It looks like 1,440 minutes of "I CAN." Every new day is a new opportunity to be greater than your limitations. Remember, "You have MS, but MS does not have YOU."

has therapists, services, and adaptive technology options to help with decisions about work and your work environment. The Americans with Disabilities Act (ADA) 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, studies have shown that pregnant woman have fewer MS relapses, especially in the second and third trimesters. Relapse rates have been shown to increase 20-40% in the first 3-6 months postpartum, although these relapses do not appear to contribute to long term disability.

Disease modifying therapies taken by the mother - or the father - may present various levels of risk before conception. You may wish to stop your MS medications before starting to have children. For a mother taking a DMT, there may be risks during pregnancy, and none are recommended for use during breastfeeding. The risks of stopping treatment prior to pregnancy and during breastfeeding should be discussed with your MS health care provider and your obstetrician.

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 have to share your diagnosis with an employer. Under the Americans with Disabilities Act (ADA), employers only need to know if you can do your job, and if reasonable accommodations are needed to help you carry out your job.

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*.

MY 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 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 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 are able to manage some chronic MS symptoms without the help of MS specialists.

KEVIN ★ ARMY

I am entirely responsible for what I do with my MS, and I think that's where perceptions will come in. How I react to reality, rather than the nature of that reality itself. How difficult and challenging something is really does come from the unique perspective of each individual. Challenges are with me daily, so I do what I can by changing my diet, daily lifestyle and going to the gym with a focus on my health and recovery.

WILLIAM ★ NAVY

In 1947 doctors were still trying to better understand MS and there were no treatments available for the disease. My neurologist told me that my body might start to show some permanent disease progression in my forties, but for the next 20 years I would likely just have "attacks" that would last between 4-7 days. He told me that I would lead a normal life and it was good to have a better understanding on what was going on, as well as what my future might look like.

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 to resolve 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 Center.

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.

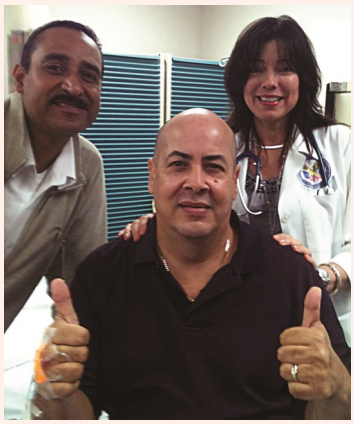
Your primary care provider focuses on your general health concerns and will coordinate with your MS specialists to address your chronic MS symptoms. Your **MS Multidisciplinary Care Team** MS specialists can help you manage relapses or other challenging MS symptoms. Other VA health care providers that specialize in mental health, urology, vision, heart, respiration, or diet may be called upon to participate in your care depending on your individual symptoms.

CLINIC APPOINTMENT PREPARATION

Below is a list of questions your MS health care professional may ask during clinic visits. It is helpful if you review these before your visit so you can update your provider.

- What medications are you taking for your MS and for your general health, including prescription and over-the-counter products?
  - Have you experienced any side-effects associated with any of your medications?
- Have you experienced any MS relapses since your last clinic visit?
  - What were the symptoms and how long did they last?
  - How are you now compared to how you were before the relapse?
- Has your MS interfered with your activities or employment?
  - If yes, what kinds of issues or problems are you experiencing?
- Are you having any memory, cognitive (thinking), or speech difficulties?
- Are you experiencing fatigue?
- Are you experiencing any depression or anxiety?
- How are you sleeping?
- Are you experiencing any pain?
  - If yes, where and how often?
- How is your mobility?
  - How often do you wobble, trip, nearly fall, or fall?
  - Do you use furniture or the walls to help you walk?
  - What type of assistance or equipment do you require?
  - Have you ever taken a medication designed to improve your walking?

- Are you experiencing any bladder difficulties such as urgency, difficulty emptying your bladder, or inability to prevent your bladder from suddenly emptying?
  - How many urinary tract infections (UTIs) have you had this year?
- Are you experiencing any bowel problems?
- Are you experiencing any spasticity or muscle spasms?
  - If yes, how often and does this interfere with your ability to function?
- Are you having any swallowing or breathing difficulties?
- What do you do for physical activity?
  - How often do you engage in physical activity?
- How is your ability to perform self-care such as bathing, dressing, transfers, eating, and other chores?
- Are you up-to-date with your vaccinations, i.e. flu, pneumonia, and pertussis?
- What type of social support do you receive from family, friends, and/or your community?
- How much tobacco do you use?
  - Have you considered smoking cessation programs?
  - How interested in quitting are you?
- How much alcohol do you use?
  - Do you feel you would benefit from drug and/or alcohol abuse programs?
- What help would improve your ability to manage your MS?



ALBERTO ★ ARMY

I would not be where I am today were it not for the encouragement and care of the Caribbean VAMC staff. They told me to NEVER GIVE UP! I was determined that while I have MS, MS does not have me.

LIFE-LONG CARE & SERVICES

VA provides a wide range of life-long health care services to Veterans with MS. 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.

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 at *www.benefits.va.gov* or *www.vets.gov*, 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
- Vision Services
- Women's Health Services
- Rehabilitation Services
- Smoking Cessation Services
- Spinal Cord Injury Services
- Substance Abuse Disorder Services
- Preventative Care
- Primary Care Services

REHABILITATIVE CARE PROGRAMS & THERAPIES

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

HOME & COMMUNITY CARE

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

PSYCHOSOCIAL CARE & SERVICES

- Caregiver Services
- Chaplain Services
- Fisher House Program for Caregivers
- Peer Activities and Counseling Program
- Post-Traumatic Stress Disorder Care
- Psychology Services
- Social Work Services

EDWARD ★ NAVY

I'm doing my best to keep myself healthy and active. I have days where I find it difficult to stay active or I can't seem to find the time to fit everything in. On those days, I remember my motivators and this helps me reach my goals. I've been married for 30 years to Barbara, a wonderful woman who provides me with limitless support. I have three amazing sons who continue to bring me a tremendous amount of joy. I'm surrounded by family and friends who care about me. I've accomplished so many things in my life and have experienced some great adventures.

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 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, VA MS website, the National Institutes of Health, reputable medical centers like the Mayo Clinic and the 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 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 clinicians 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.

LINDSAY ★ NAVY

What label do I want to be known by? It is my choice, and my actions will determine who I think I am, and ultimately who I become. One choice I have made is to continue living my life. MS may slow me down sometime in the future, but I could never predict when that may be, nor can my doctor. For now, I keep in mind the couple on the side of a mountain: a mountain that had brought a 21-year-old to her knees, and the older couple that were laughing about "shaking it up a little" and climbing it twice.

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 specialist about getting your vitamin D level checked, and about whether you should add a supplement.

For more information about healthy food choices you may want to 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.

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.

Primary care and **specialty care evaluations** should take place regularly. Primary Care providers and MS specialists 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, weakened immune system, or it might make a current health condition worse. VA offers a variety of programs to help manage personal stress, and 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.

> It is important to work with your rehabilitation team to select the most appropriate exercise program than can be adapted to your changing needs.

VA has a special program that combines eating well and exercise called **MOVE!** (*www.move.va.gov*). This program is available at all VA medical centers. **MOVE!** 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.

VA BENEFITS FOR VETERANS WITH MS

Veterans may be eligible for a broad range of programs, services, and benefits that are based upon enrollment eligibility and honorable discharge from military service. Eligibility for VA's comprehensive medical benefits package is determined following the submission of your enrollment application. 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. Nonservice-connected status refers to Veterans who have a disability or health issue that is not related to their military service. For information on VA health care, call 877-222-8387 or visit *www.va.gov/health*.

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. To determine your eligibility for service-connected or nonservice-connected disability status you need to apply for health benefits. Once that is completed, the best way to apply for benefits are online at *www.eBenefits.va.gov* or you can visit the enrollment office at your local VA facility. Additional information on benefits can be found at the Veterans Benefits Administration homepage *www.benefits.va.gov* or call 800-827-1000.

For more information and support, contact your local VA medical center social work department, VA patient advocates department, or one of the Veterans Service Organizations like Paralyzed Veterans of America or Disabled American Veterans.

CHARLES ★ ARMY

Since I learned that I have MS, I have gone sky diving and my wife and I stay busy by traveling. I have also enjoyed being very active in helping other people with MS by encouraging them to stay on track with their MS medications. I think it is important for Veterans to be aware of the many programs the VA has to offer them. The VA has helped me and my family. I am a second generation Veteran and I have not let MS control my life, instead I am in control of it!

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 the majority of programs.**

FAMILY SUPPORT

VA has a number of 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, visit *www.caregiver.va.gov/*, or call the VA Caregiver Support Line at 855-260-3274.

GOVERNMENT & COMMUNITY RESOURCES

GOVERNMENT AGENCIES

US Department of Veterans Affairs (VA) is comprised of three organizations, the Veterans Health Administration (VHA), Veterans Benefits Administration (VBA), and National Cemetery Administration (NCA). VHA operates one of the largest health care systems in the world and provides training for a majority of America's medical, nursing, and allied health professionals. More than nine million Veterans are enrolled in VA health care services. (*www.va.gov* or *www.vets.gov* | 877-222-8387)

My Health*e*Vet is VA's online personal health record. It was designed for Veterans, Servicemembers, their caregivers, and others. Using My Health*e*Vet can help you gain a better understanding of your health status. It allows you to explore different ways you can monitor and improve your health. When you use the tools on My Health*e*Vet, you become a more active partner with your health care team. The great benefit is that you can easily access your personal health information in your My Health*e*Vet account - anytime and anywhere you have Internet access. (*www.myhealth.va.gov* | 877-327-0022)

The **Veterans Health Library** is a one-stop source for Veteran-focused health information to help Veterans stay well and well-informed. There are over 1,500 health sheets, over 150 videos, Go-to-Guides, and Flipbooks that have been approved by VA experts. All health information is available to Veterans, their family, and the public, no matter where the Veteran receives care. (*www.veteranshealthlibrary.org*)

Veterans Affairs MS Centers of Excellence (MSCoE) 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 increase and improve health care services and quality of life for Veterans with MS. (*www.va.gov/ms* | 503-273-5191)

National Institute of Health (NIH) is part of the US Department of Health and Human Services. NIH is the nation's medical research agency - making important discoveries that improve health and save lives. The **NIH Clinical Trials** website provides access to information on publicly and privately funded clinical studies on a wide range of diseases and conditions. Visitors to the site can find and view clinical studies based on the topic or location, as well as learn about clinical research. (*www.clinicaltrials.gov*)

The **US National Library of Medicine: MedlinePlus** is the world's largest medical library. It provides up-to-date information on diseases and conditions, prescription and non-prescription drugs, wellness issues, and clinical trials. You can use MedlinePlus to learn about the latest treatments, look

up information on a drug or supplement, find out the meanings of words, or view medical videos or illustrations. (*https://medlineplus.gov/*)

DISABILITY VETERANS SERVICE ORGANIZATIONS (VSO)

Disabled American Veterans (DAV) is chartered by the US Congress for military Veterans as a Veterans' advocacy and assistance group. Their mission is to fulfill our country's promises to the men and women who served, to empower Veterans to lead high-quality lives with respect and dignity, and to meet the needs of Veterans transitioning back to civilian life. (*www.dav.org* | 877-426-2838)

Paralyzed Veterans of America (PVA) is a congressionally chartered Veterans service organization that has developed a unique expertise on a wide variety of issues involving the special needs of Veterans of the armed forces who have experienced spinal cord injury or dysfunction. PVA uses that expertise to advocate for quality health care, research and education addressing spinal cord injury and dysfunction, benefits as a result of military service, and civil rights and opportunities that maximize independence. (*www.pva.org* | 800-424-8200)

NOT-FOR-PROFIT MS ORGANIZATIONS

MS Association of America (MSAA) offers programs and services to assist people with the ever-changing course of MS. Their Shared Management philosophy, involving education, training, use of technology, and tools to promote healthy outcomes, is a concept whereby both the patient and health care providers work together to achieve the best possible health outcomes for the patient. MSAA's programs and services have been developed to help members of the MS

TONIA ★ ARMY

I've been an Ambassador for the National MS Society in Salt Lake City since 1999. I'm actively involved in the NMSS MS Walk event in April and NMSS MS Bike event in June. Being involved with these events gives me the opportunity to meet new people with MS each year, as well as their families and friends. It's fun to meet so many people and I'm always surprised by how many people have MS.

community be proactive, taking steps toward better health and an improved quality of life. (*www.mymsaa.org* | 800-532-7667)

MS Foundation (MSF) provides a comprehensive approach to helping people with MS maintain their health and well-being. They offer programming and support to keep people with MS self-sufficient and their homes safe, while their educational programs heighten public awareness and promote understanding about MS. MSF resources assist people who have MS, their families and caregivers, regional support groups, and health care professionals. (*www.msfocus.org* | 800-225-6495)

MSWorld.org is managed by an all-volunteer team who is living with or affected by MS. Their mission is to end the isolation that people experience when diagnosed with MS through the creation of an online community where people can come together for support. MSWorld offers chat rooms, message boards, and networking connections (Facebook, Twitter), as well as a wellness center, creative center, and resource center. (*www.msworld.org*)

National MS Society (Society) supports MS research, services for people with MS, provides professional education programs, and furthers worldwide MS advocacy efforts. The Society's Professional Resource Center has the most comprehensive library of MS information in the world. Their goal is to partner with health care professionals to enhance quality of care and increase access to care for people with MS. Their vision: A World Free of MS. (*www.nationalmssociety.org* | 800-344-4867)

United Spinal Association (United Spinal) is dedicated to enhancing the quality of life for people living with spinal cord injuries and disorders (SCI/D), providing support and information to loved ones, care providers, and health care professionals. United Spinal is committed to providing active-lifestyle information, peer support, and advocacy that empowers individuals to maximize their independence, remain active in their communities, and achieve their highest potential in all facets of life. (*www.unitedspinal.org* | 718-803-3782)

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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 at 800-949-1004, ext. 53296, 503-273-5191, or *MSCentersofExcellence@va.gov*.

Visit our website *www.va.gov/ms* for content updates.

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