

What Do I Need to Know?



Some Facts

What is Multiple Sclerosis?

Multiple sclerosis (MS) is an unpredictable, often disabling disease of the central nervous system that interrupts the flow of information within the brain and between the brain and the body and stops people from moving. Symptoms range from numbness and tingling to blindness and paralysis. The progress, severity, and specific symptoms of MS in any one person cannot yet be predicted.

Treatment may include:

Treatments for MS focus on controlling the immune system and managing symptoms. It is important for people to work with their health care providers to find the best approach to address MS symptoms like extreme fatigue, bladder problems, and muscle spasms. MS symptoms, both mental and physical, can be managed with conventional medication, complementary and alternative medicine, physical therapy, mobility devices, psychotherapy, medication, and other self-care approaches.

Physical and Mental Changes to Expect

Symptoms of multiple sclerosis (MS) can vary greatly from Veteran to Veteran and from time to time in the same person. For instance, one person with MS may experience abnormal fatigue and another person may have severe vision problems. While one person with MS may have loss of balance, muscle coordination or tremors — making walking and everyday tasks difficult to perform — another person may have slurred speech and memory issues. These problems may be permanent or may come and go.

Depression is frequently experienced by MS patients and can have a significant impact on quality of life.

Physical changes may include: visual disturbances; difficulty in controlling strength and movements; impaired coordination and balance; numbness; tingling; sensitivity to heat and cold; bladder control problems; urinary tract infections; mild to severe fatigue and weakness

Mental changes may include: problems with memory and concentration

Emotional changes may include: mood swings, ranging from depression to euphoria

What Does This Mean for Me?

MS affects not only the Veterans with the illness, but also family members and friends. Caring for someone with a chronic illness like MS can be deeply satisfying. Spouses and partners, family, and friends can be drawn more closely together by their shared concerns and collaborative efforts. While the primary Caregiver is most often a partner or spouse, it may also be an adult child, parent, or friend. Whoever you are, remember that paying attention to your own health and well-being is essential to being able to care for someone else.

At times, caring for a Veteran with MS can be physically and emotionally exhausting, particularly for the primary Caregiver. Because symptoms of MS typically fluctuate, it can make caregiving a challenge — you may find it hard to anticipate the next symptom or need of the Veteran you are caring for. These reactions are normal, but can be challenging to deal with on your own. Remember that it's okay to ask for help and that support is available through a variety of avenues. Friends, family, support groups and professional mental health practitioners are all good resources.

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Caregiving Tips

1. Educate yourself. Understanding MS and its related physical and emotional symptoms will help you and the Veteran you care for cope with and manage the disease.
2. Pay attention to warning signs of depression. If you begin to notice the Veteran is displaying signs of depression, take action. Keep contact information for a psychiatrist and/or therapist, local crisis team, Veterans Crisis Line (1-800-273-TALK[8255]), and other emergency phone numbers handy. If any Veteran talks about suicide, **take it seriously** and seek help immediately.
3. It is important for your health as well as the health of the Veteran with MS that you take some time off (or “respite”) from caregiving.
4. Seek out emotional support. It is important that you feel comfortable discussing your concerns and fears openly.
5. Plan to re-evaluate schedules and task assignments as needs and circumstances change. Make sure to schedule personal time for everyone in the household.
6. If a task seems impossibly difficult or stressful, there may be an easier way to do it. Reach out to your family and friends for support or suggestions. The VA medical team can also provide tips, techniques, and sometimes even equipment for bathing, dressing, and safe transfers.
7. Leaving the Veteran home alone can be a frightening proposition for both of you, especially if the Veteran has significant disabilities. Advance planning and making adaptations to your home can help to decrease these worries. Accessible peepholes in the front door, portable telephones with speed dial, automatic door openers, and “life-net” call systems that summon help in an emergency may provide security and peace of mind.
8. Caregivers can and should make appointments with healthcare professionals to get information, advice, and training. Having a support team of committed medical experts can help you to feel at ease, determine the best treatments for the Veteran, and ensure that you understand medical procedures and instructions. Caring for a Veteran with MS can be confusing, so it is important that you surround yourself with a team that can help you navigate the caregiving system.
9. Visit your doctor regularly for YOUR needs, and get plenty of rest so you can stay strong. Remember, you are doing the best you can and you are making a difference in your loved one’s life. Your health is essential to your ability to keep providing for the Veteran you care for.



I have more questions. Where can I go for help?

VA knows that being a Caregiver can be both rewarding and hard. You can always find more information at www.caregiver.va.gov, including contact information for the VA Caregiver Support Coordinator near you.

You can also call VA’s Caregiver Support Line
toll-free at 1-855-260-3274.

The Caregiver Support Line is open
Monday through Friday, 8:00 am – 11:00 pm ET,
and Saturday, 10:30 am – 6:00 pm ET.

Call to talk to caring professionals who can:

- Tell you about assistance available from VA.
- Help you access services and benefits.
- Connect you with your local Caregiver Support Coordinator at a VA Medical Center near you.
- Just listen, if that’s what you need right now.

Multiple Sclerosis Center of Excellence: <http://www.va.gov/MS/index.asp>

Multiple Sclerosis Fact Sheet: <http://www.nationalmssociety.org/living-with-multiple-sclerosis/veterans-with-ms/index.aspx> (supported VA resource)

PLAINTALK: A Booklet About MS for Families (.pdf) discusses some of the more difficult physical and emotional problems many families face