What’s New in VA Caregiving?

Emotional Changes in the Veteran with Multiple Sclerosis (MS): Tips for the MS Caregiver
By Margaret Kazmierski, MSW, LCSW-C, MSCS and Alicia Sloan, MPH, MSW, LICSW, VA Multiple Sclerosis Centers of Excellence (MSCOE)

Multiple sclerosis is a complex disease that affects the central nervous system, including the brain, spinal cord and optic pathways. It is characterized by relapses and remissions. Relapses are neurologic symptoms which can appear rapidly over a few days and then improve to some extent over weeks or months. Remissions are periods of time when a person may not have any new symptoms. The disease can be unpredictable and include a variety of symptoms that can worsen or progress over time (Costello, www.va.gov/MS/About_MS.asp, 2009.) MS can affect the ability to walk or complete a physical task. It can also affect the ability to regulate emotions and mood. Emotional changes like depression or anxiety can be less visible and may not be as obvious as physical changes like gait change or falling that are remedied by using a cane, walker or wheelchair. However, the emotional aspects of MS are just as important and can be as debilitating as the physical changes that occur with the disease. Many individuals diagnosed with MS have reported that emotional changes have been some of the most challenging symptoms to cope with and they can have a profound emotional effect on the Caregiver.

Understanding how MS affects your loved one on an emotional level may help you as you cope with your own feelings and the stress and challenges in your role as a Caregiver. The first thing to remember is that emotional changes in a person with MS can be from different aspects of MS. Changes can be “reactionary,” an emotional reaction to the diagnosis and physical changes and the challenges of daily living with MS. Emotional changes in individuals with MS can be the result of the physical damage to the nervous system caused by MS. Emotional changes can also be a result of side effects from certain medications used for MS. Certain medications prescribed for MS symptoms and disease progression can also affect mood. Corticosteroids are sometimes prescribed to treat MS exacerbations and can cause mood swings for some individuals. All four of the interferon-beta medications (Avonex, Betaseron, Extavia and Rebif) used to treat MS can cause or increase depression. If your loved one does experience a significant mood change while taking corticosteroids or an interferon, the MS care team should be alerted immediately.
Emotional changes observed in individuals with MS:
• Depressive episodes (mild to severe)
• Grief
• Anxiety
• Stress
• Mood swings
• Uncontrollable laughing and/or crying

Additionally, research has identified certain emotional and physical symptoms of MS that can increase the emotional and physical burden on Caregivers (Dunn, 2011; NAC/NMSS Multiple Sclerosis Caregivers Report, 2012.).

MS symptoms that can increase burden on Caregivers:
• Difficulty walking
• Cognitive impairments (memory, attention, thinking)
• Depression/anxiety
• Frequency of bladder dysfunction
• Instability of MS symptoms

Emotional changes can also have a ripple effect on family, friends and especially Caregivers, who may be providing all of the physical/hands-on care to the Veteran with MS. Caregivers can even experience similar emotions and health problems as they witness emotional changes in their loved ones with MS (Dunn, 2011). Notice how many Caregiver health problems mirror the care recipient’s MS symptoms?

Caregiver Health Problems:
• Tiredness
• Depression
• Back pain
• Insomnia
• Shortness of breath

Successful Caregivers learn to seek help from others and create a supportive network to help them cope with Caregiver stress. It may be helpful to know that new Caregivers or Caregivers who may be burned out or going through an especially challenging time may experience different phases in their decision to seek and accept support. One study (McKeown, 2004) with MS Caregivers identified phases that Caregivers may go through when asking for help. If you do find yourself struggling with asking for help, it may help to identify the phase you are experiencing and know it’s a normal reaction to being a Caregiver. You may even find yourself repeating these phases as you experience different Caregiving situations.

Phases of Decision to Seek and Accept Support:
• Rejecting support
• Resisting support
• Seeking support
• Accepting support
As you go through the phases of seeking and accepting support, it is helpful to have tips to help you manage the stress and emotions you may experience during the
more challenging times. Listed below are some helpful tips and resources for MS Caregivers to help manage stress. The important thing to remember is that you are not alone and there is help and support out there to help you as an MS Caregiver.

- Know who the Caregiver Support Coordinator and MS Social Worker are at your VA. You can look up your Caregiver Coordinator on the VA website: [www.caregiver.va.gov](http://www.caregiver.va.gov) or call 1-855-260-3274. Your VA MS Care Team can tell you who the Social Worker is for the MS clinic.
- Making use of Caregiver tools and resources online can simplify a “chaotic” schedule and care plan. The VA Caregiver website has a great Caregiver workbook and other tools specific to VA Caregivers.
- Know that you cannot control the MS disease process, but you can control many aspects of how it affects you and your loved one with MS.
- Remember you are doing the best you can at the moment. Take one day at a time.
- Recognize you have to take care of yourself to take care of your loved one with MS.
- Take advantage of respite care offered by VA. Talk to your VA Caregiver Coordinator or Social Worker about how to get respite services and plan for a break.
- Recognize your limits and reach out to others to help you. Let go of “hypervigilance” and being a “martyr” – accept help where you can.
- Listen to your emotions and acknowledge them.
- Think about constructive ways to deal with stress and expressing your feelings. Meditation, regular exercise, a Caregiver support group or journal writing are all ways to relieve stress and express your feelings. Meditation and deep breathing exercises or a quick walk can help even if it’s only for a few minutes a day.
- Remember to laugh and have a sense of humor. Laughter can also help you breathe more and has many physical and mental benefits.
- Taking time out for yourself is important! Plan regularly scheduled breaks. Don’t wait until you are stressed and burned out.
- Take care of your health. Make sure to incorporate regular medical exams, exercise and nutritious meals and snacks into your daily schedule.
- Plan fun and supportive activities with friends, family and loved ones, in addition to your loved one with MS. Maintain your friendships and meaningful activities.
- Seek out spiritual support and nourish your spiritual life, whether it is going to church, meditation, prayer or a walk in nature.
- Read the Twelve Steps for Caregivers: [www.rush.edu/rumc/page-R13418.html](http://www.rush.edu/rumc/page-R13418.html).
- Join a MS Caregiver support group in your area or call the monthly support group offered by the VA MS Centers of Excellence. This is a monthly call offered on the fourth Monday of every month to MS Caregivers and family members who need emotional support and resources. To find out more information about the calls, visit the VA MS Centers of Excellence website ([www.va.gov/MS/articles/Education/Free_Monthly_Educational_Conference_Call_s.asp](http://www.va.gov/MS/articles/Education/Free_Monthly_Educational_Conference_Call_s.asp)). To participate in the monthly calls, use the following dial-in information:
  - Dial 1-800-767-1750, then punch in 43157#.
MS Specific Websites for Caregivers

• VA Caregiver Website Toolbox: www.caregiver.va.gov/toolbox_landing.asp
• Caregiver Workbook: www.caregiver.va.gov/pdfs/Caregiver_Workbook_V3_Module_1.pdf
• VA MSCOE Website: www.va.gov/ms
• Communication Tips & Assisting a Caregiver: www.familycaring101.org/assist
  www.familycaring101.org/assist/communicating.cfm
• Consortium of MS Centers (CMSC): www.mscare.org/cmsc/News/Web-Sights-MS-Caregivers-2.html
• Caring for Loved Ones with Advanced MS: A Guide for Families, editors: Dorothy E. Northrop, MSW, ACSW and Debra Frankel, MS, OTR. National MS Society.
• Paralyzed Veterans of America: www.pva.org/site/c.aiIRK9NJLcJ2E/b.6306123/k.B389/Caregivers_Support.htm
• Rosalynn Carter Institute for Caregiving: www.rosalynncarter.org
• Aging Care: www.agingcare.com/Caregiver-Support
• Powerful Tools for Caregivers: www.powerfultoolsforcaregivers.org

Community Resources

• The National Alliance for Caregiving: www.caregiving.org
• Powerful Tools for Caregivers: www.powerfultoolsforcaregivers.org
• Today’s Caregiver Magazine: www.caregiver.com
• National Family Caregivers Association: www.nfcacares.org
• Caregivers Community: www.caregiverscommunity.com