Depression and Suicide Risk in MS: How Caregivers Can Help!

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“It is our hope that practitioners implement evidence-based practices to demonstrate that supportive services result in a healthier caregiver, an improved quality of care for the veteran, and a better quality of life for both the caregiver and the veteran.”

(Carol J. Sheets, LICSW, ACSW, VA National Director of Social Work, and Heather Mahoney-Gleason, LICSW, National Caregiver Support Program Manager, 2010)
Caregivers Can be at Risk, too...

• Depression/Anxiety
• Lower Quality of Life
• Self-esteem/Self-efficacy: How you feel about yourself!
• Other health problems:
  • Back pain
  • Fatigue
  • Insomnia
  • Shortness of breath

(Buhse, et al., 2015; Ghafari et al, 2014; Adelman, et al., 2014; Chen and Habermann, 2013; O’Connor and McCabe, 2011; Kahn, et al., 2007; Schultz and Beach, 1999)
Caregivers and Quality of Life

CG has a poorer Quality of Life if...

• A spouse
• Longer duration of caregiving
• Loved one has moderate or worse MS symptoms
• Unstable MS disease course

(Buhse, et al., 2015; Ghafari et al, 2014; Adelman, et al., 2014; Chen and Habermann, 2013; O’Connor and McCabe, 2011; Kahn, et al., 2007; Schultz and Beach, 1999)
MS Symptoms That Can Increase Caregiver Burden

- Difficulty walking, balance
- Ataxia
- Fatigue
- Pain
- Incontinence
- Cognitive Impairments
- Depression/anxiety
- Bladder dysfunction
- Instability of symptoms
- Advanced MS symptoms

(Kumpfel, et al., 2007; Dunn, 2011; Bowen, et al., 2011; MS Caregivers Report, 2012; Chen and Habermann, 2013)
MS Caregiver Burden

- Physically Exhausted: 50%
- Depression: 33%
- Financial pressure: 43%
- Physical Injury: 17%
- Hobbies: 22%
- Lost job b/c of CG: 33%
- Can't work due to CG: 43%

(MS Caregivers Report, 2012)
We Encourage Caregivers to get support...

National VA Caregiver Support Line:

Most common reasons for calling

• Benefits
• In-home support services
• General Caregiver support/education
• Navigating the VA
• Questions about the Program of Comprehensive Assistance for Family Caregivers.

(Malcolm, 2015; Wright, Malcolm, Hicken & Rupper, 2015)
Understanding Depression in MS can Help…

Caregivers, friends, and family who understand Depression in MS can better help their loved one with MS.

Adults with MS
• 1 in 4 chance of developing depression in their lifetime.
• 40-60% have reported depression symptoms
• 15.7% have DSM-V definition of depression (major depression, etc.)

Why?
• Depression & fatigue in MS is due to complex interactions in immune system and neuroendocrine system, and...
• Damage to areas in the frontal lobe in brain.

Depression is more common in MS when...

- Earlier in the disease process... as people come to terms with MS diagnosis.
- When there is More Disability or trouble with Ambulation
- When there is Less Self-Care activities (physical activity, etc.)
- During periods of MS relapse.

(Systematic Review of literature in Current Neurology and Neuroscience Reports, Turner, et al., in press, 2016)
Veterans with MS and their Caregivers

• MSCOE study
• 451 Veterans with MS receiving care at VA
• Less depression if Veteran perceived they had...
  – Greater social support
  – Positive social interaction
  – Greater emotional/information support
  – Expressed affection

(Bambara, et al., 2010)
Fatigue and Depression – Double Whammy!

- Fatigue: 90% in people with MS
- Fatigue and depression can be hard to tell apart
- Significantly reduce patients’ quality of life
- Reduce participation in daily activities.
- Less likely to do self care and positive activities (exercise, social activities, medication adherence) while depressed or fatigued.
  - More likely to use alcohol/substance abuse
  - More likely to stop MS disease modifying medications.

(Systematic Review of literature in Current Neurology and Neuroscience Reports, Turner, et al., in press, 2016)
Self-Care: What Helps?

• Both of you! Increase Self Care activities, Social Support & Activities
• Get involved with groups: Caregiver groups, MS and Veteran Service Organizations
• Maintain Personal Relationships with Friends and Family, Social Life
• Talk to your loved one with MS about their depression & fatigue: How does depression show up for them? (sadness, loneliness, boredom, feeling suicidal)
• Discuss Treatment Options with your Medical Provider/Mental Health Provider
• Physical activity: Increase it!
• Motto: 5 -10 minutes of activity is better than nothing.
• Outside sunlight: at least 10 minutes a day of natural Vitamin D
Increase Self-Care Activities…

• What do you like to do to make yourself feel better or more safe?

  – Ex: Walking, listening to music, exercise, watching sunsets, gardening, meditation, yoga, reading, writing in journal
The Elephant in the Room...Suicide

Sometimes, even if I stand in the middle of the room, no one acknowledges me.
Let’s look at the whole picture
U.S. Suicide Statistics

• 10th leading cause of death in U.S.
• Cultural, regional & demographic differences
• Over 1 million attempts annually
• General population: 13.5% have thoughts of suicide (suicidal ideation); 4.6% attempt suicide

(from presentation at Consortium of MS Centers, Christine Moutier, MD, American Foundation for Suicide Prevention

There are Different Models Experts Use to Understand Suicide

Interacting Risk and Protective Factors

- Biological factors
- Psychological factors
- Social & Environmental factors
- Current Life Events

(from presentation at Consortium of MS Centers, Christine Moutier, MD, American Foundation for Suicide Prevention
Suicide is the result of an interaction between environmental stressors and a trait-like diathesis (susceptibility to suicidal behavior) independent of psychiatric disorders.

**Diathesis/Threshold Variables**
- Predisposition to illness & stress needed for it to happen
- Mental illness
- Aggressions/impulsivity
- Poor adaptability/problem-solving
- Family history of suicide or mental disorder
- Childhood abuse
- Early loss
- Head injury
- Genetics
- Low serotoninergic functioning: Low levels of serotonin
  - **Chronic illness**
  - Chronic substance abuse
  - **Chronic pain**
  - **Cognitive factors (decision making)**

**Stress/Triggers**
- Acute psychiatric episode (e.g., Depression, psychosis)
- Acute medical illness
- Stressful life event
- Acute substance use
- Psychological pain
- Panic attacks
America is in a public health crisis - rate of suicide on the rise

Recent study: 20 Veterans died from suicide each day.

66% from firearm injuries.

65% are 50 years or older.

Risk Compared to U.S. civilian adults:

- 21% higher among Veterans
- 18% higher among male Veterans.
- 2.4 times higher among female Veterans

(VA Suicide Prevention Program: Facts about Veteran Suicide, July 2016)
MS Centers of Excellence Study

- 445 Veterans with MS
- Mailed surveys linked with VHA computerized medical records
- Patient Health Questionnaire (PHQ): suicide item
- 29.4% suicidal ideation (~5% higher than Feinstein study of civilian outpatients)
- 7.9% persistent suicidal ideation over the last 2 weeks
- Suicidal ideation was associated with...
  - Younger age
  - Earlier disease course
  - Progressive disease subtype
  - Lower income
  - Not being married
  - Lower social support
  - Not driving
  - Higher levels of physical disability (mobility, bowel, bladder)
  - Depression

(Turner, et al., 2006)
People with MS and Suicide Risk

• People with MS are at **higher risk** for Suicide:
  • Twice as much at risk than general population.
  • Predictors:
    – Depression, Anxiety, other mental health difficulties
    – Being Younger
    – Male
    – Early in diagnosis (first few years)
    – Later as disability cumulates.
  • Recommend that providers specifically screen for suicidality while screening for depression.

(Systematic Review of literature in Current Neurology and Neuroscience Reports, Turner, et al., in press, 2016)
Specific Studies: Suicide Risk – MS

Outpatient MS Clinic

- 28.6% endorsed lifetime suicidal ideation
- Living alone
- Family history of mental illness
- Social stress
- Major depression
- Anxiety disorder
- Alcohol abuse

(Feinstein, 2002)
Restricting Access Helps

• Restricting access to lethal means saves lives.
• Lock up or remove guns, stockpiled pills, knives, etc.

Caregivers Can Help:
Suicide Prevention Checklist

- **Power of 1:** One simple act has the power to make a difference to your loved one going through a difficult time...Reach Out!
- **Make a connection:** Let your loved one know “You’re not alone. “ Ask “Are You OK?”
- **Talk to your loved one:** about feelings/thoughts of suicide: **Don’t be afraid to ask** clearly and directly: “**Are you having thoughts about suicide?”**
- **Listen:** to their story, feelings, thoughts without judgment.
- **Reasons to Live “Turning Point to Life” & Choices:** Talk with them about what’s important to them and reasons to live. Talk about choices that can happen now.
- **Talk about Safety-for-Now Solutions:** Develop a safety for now plan. What can I do to help you stay safe? (lock up firearm, take pills away, etc.)
- **Safety Plan:** [http://www.suicidepreventionlifeline.org/Learn/Safety](http://www.suicidepreventionlifeline.org/Learn/Safety)
- **Call Crisis Line together:** 1-800-273-TALK (8255) press 1 for Veterans
- **Call VA:** MS Care Team, Mental Health Provider, Primary Care Provider
- **Ask for Other Support:** from other friends/family/neighbors/support system
- **In Emergency:** Call 911
How To Talk to Your Loved One Who Is Talking About Suicide

• Be direct. Talk openly and matter-of-factly about suicide.
• Be willing to listen. Allow expressions of feelings. Accept the feelings.
• Be non-judgmental. Don't debate whether suicide is right or wrong, or whether feelings are good or bad. Don't lecture on the value of life.
• Get involved. Become available. Show interest and support.
• Don't dare him or her to do it.
• Don't act shocked. This will put distance between you.
• Don't be sworn to secrecy. Seek support.
• Offer hope that alternatives are available but do not offer glib reassurance.
• Take action. Remove means, such as guns or stockpiled pills.
• Get help from persons or agencies specializing in crisis intervention and suicide prevention.
• **Call 1-800-273-TALK (8255) press 1 for Veterans**

(from [www.suicidepreventionlifeline.org/gethelp/someone.aspx](http://www.suicidepreventionlifeline.org/gethelp/someone.aspx))
Be Aware of Feelings

• Many people at some time in their lives think about suicide.
• Most decide to live because they eventually come to realize that the crisis is temporary and death is permanent.
• On the other hand, people having a crisis sometimes perceive their dilemma as inescapable and feel an utter loss of control.
• These are some of the feelings and thoughts they experience:
  – Can't stop the pain
  – Can't think clearly
  – Can't make decisions
  – Can't see any way out
  – Can't sleep, eat or work
  – Can't get out of depression
  – Can't make the sadness go away
  – Can't see a future without pain
  – Can't see themselves as worthwhile
  – Can't get someone's attention
  – Can't seem to get control

(from http://www.suicidepreventionlifeline.org/gethelp/someone.aspx)
Know the Warning Signs

Depression, anxiety, low self-esteem, hopelessness, such as:

- Appearing sad or depressed most of the time
- Clinical depression: deep sadness, loss of interest, trouble sleeping and eating—that doesn’t go away or continues to get worse
- Feeling anxious, agitated, or unable to sleep
- Neglecting personal welfare, deteriorating physical appearance
- Withdrawing from friends, family, and society, or sleeping all the time
- Losing interest in hobbies, work, school, or other things one used to care about
- Frequent and dramatic mood changes
- Expressing feelings of excessive guilt or shame
- Feelings of failure or decreased performance
- Feeling that life is not worth living, having no sense of purpose in life
- Talk about feeling trapped—like there is no way out of a situation
- Having feelings of desperation, and saying that there’s no solution to their problems
Know the Warning Signs

• If your loved one’s behavior is dramatically different from their normal behavior, or...
• Appears to be actively contemplating
• Preparing for a suicidal act through behaviors, such as:
  – Performing poorly at work or school
  – Acting recklessly or engaging in risky activities—seemingly without thinking
  – Showing violent behavior such as punching holes in walls, getting into fights or self-destructive violence; feeling rage or uncontrolled anger or seeking revenge
  – Looking as though one has a “death wish,” tempting fate by taking risks that could lead to death, such as driving fast or running red lights
  – Giving away prized possessions
  – Putting affairs in order, tying up loose ends, and/or making out a will
  – Seeking access to firearms, pills, or other means of harming oneself
Social Media and Suicide Prevention

• Facebook, Twitter, MySpace, YouTube, Tumblr, etc.
• Friend posts about...
  – wanting to die or to kill oneself.
  – feeling hopeless or having no reason to live.
  – feeling trapped or in unbearable pain.
  – being a burden to others.
  – seeking revenge.
• Encourage Friend to call the crisis line.
• Facebook has a suicide prevention safety feature on “Report Post”

www-suicidepreventionlifeline.org/media/12919/FB-One-Pager-for-AAS-3-.pdf
VA Aggressively Undertaking New Measures to Prevent Suicide

- Each VA has a Suicide Prevention Coordinator
- **Veterans Crisis Line Expansion** –
- 1-800-273-TALK (8255) and then “Press 1”
- Enhanced provision of care to women Veterans
- Expanding TeleMental Health Services
Crisis Lines

- National Suicide Prevention Lifeline: [www.suicidepreventionlifeline.org](http://www.suicidepreventionlifeline.org)
  1-800-273-TALK (8255)
- Veterans Crisis Line: [www.veteranscrisisline.net](http://www.veteranscrisisline.net)
  1-800-273-TALK (8255) press 1
Peer to Peer Suicide Prevention & Intervention Training

Community/peer interactive training in suicide first-aid skills

• Applied Suicide Intervention Skills Training (ASIST)
• Other workshops: SAFE TALK, Suicide to Hope
  • Created by evidence – based research at www.livingworks.net
  • Washington State: National Guard offers ASIST workshops to Veterans and their families once a month for free

National Guard & Reserve Members, Family, Friends
http://usmilitarymatters.org  Free online training & resources
Other VA Resources for Caregivers

Coaching Into Care: 1-888-823-7458

www.va.gov/coachingintocare

• Assists family members and friends to help a Veteran seek care.
Free Self-Care Apps

- PTSD Coach:  [www.ptsd.va.gov](http://www.ptsd.va.gov)
- Mindfulness Coach
- Moving Forward (problem solving skills)
  [https://mobile.va.gov/app/moving-forward](https://mobile.va.gov/app/moving-forward)
Suicide Prevention Resources

- VA Make the Connection: Connection to resources and Veterans stories: [https://maketheconnection.net](https://maketheconnection.net)
- Veterans Crisis Line: [www.veteranscrisisline.net](http://www.veteranscrisisline.net)
- The Power of 1: [www.veteranscrisisline.net/ThePowerof1.aspx](http://www.veteranscrisisline.net/ThePowerof1.aspx)
- American Foundation for Suicide Prevention: [www.afsp.org](http://www.afsp.org)
- Suicide Prevention Lifeline: [www.suicidepreventionlifeline.org](http://www.suicidepreventionlifeline.org)
- American Association of Suicidology: [www.suicidology.org](http://www.suicidology.org)
Caregiver Resources

VA MS Centers of Excellence (MSCoE) Website: www.va.gov/MS
❖ MS Caregiver page: www.va.gov/MS/veterans/caregivers

VHA Resources
❖ VA Caregiver support line: (855) 260-3274   www.caregiver.va.gov
  • Online Caregiver Workshop: https://va.buildingbettercaregivers.org
  • Caregiver Workbook: www.caregiver.va.gov/pdfs/Caregiver_Workbook_V3_Module_1.pdf
❖ VA Respite Care: www.va.gov/GERIATRICS/Guide/LongTermCare/Respite_Care.asp

Paralyzed Veterans of America (PVA) Caregiver Support

MS Organizations:
❖ National MS Society: www.nationalmssociety.org
Family and Relationships:
  www.nationalmssociety.org/Living-Well-With-MS/Family-and-Relationships
Family Matters: www.nationalmssociety.org/Resources-Support/Family-Matters
❖ Multiple Sclerosis International Foundation: www.msif.org
Caregiving and MS: MS in focus magazine, Issue 9, www.msif.org/living-with-ms/ms-in-focus-magazine
Family Life: www.msif.org/living-with-ms/family-life
❖ MS Association of America: www.mymsaa.org
Care Partner Resources http://mymsaa.org/journey/the-seasoned-traveler

Sloan Caregiver Call, 2016