MS Caregiver Matters

Education and Support - Just a Phone Call Away!

PVA Summit
August 27, 2013
Orlando, FL

VA Care Management and Social Work Service
Care and Compassion across the Continuum
Learning Objectives:

1. Describe characteristics (epidemiology) of the Caregiver and what is unique to Caregivers of Veterans with multiple sclerosis.
2. Understand how the results from Caregiver studies by MSCOE and other major Caregiver studies support the need for outreach and support of Caregivers of Veterans with multiple sclerosis.
3. Understand the elements of psycho-education and emotional support dedicated to Caregivers of Veterans with multiple sclerosis.
4. Understand how increasing the access to resources via the internet and telephone may help Caregivers of Veterans with multiple sclerosis.

Sloan & Kazmierski, PVA Summit 2013
Disclosures

The presenters of this session have nothing to disclose.

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Presenters

- Alicia P. Sloan, MPH, MSW, LICSW
  Research Social Worker, Research & Special Projects Coordinator
  MS Center of Excellence-West, Veterans Health Administration
  Veterans Affairs Puget Sound Health Care System, Seattle, WA
  alicia.sloan@va.gov

- Margaret Kazmierski, MSW, LCSW-C, MSCS
  Clinical Social Worker, Spinal Cord Injury Coordinator
  MS Center of Excellence-East, Veterans Health Administration
  VA Maryland Health Care System, Baltimore, MD
  margaret.kazmierski@va.gov
MS Caregiver Matters: Epidemiology of the MS Caregiver

Alicia P. Sloan, MPH, MSW, LICSW
Research Social Worker, Research & Special Projects Coordinator
MS Center of Excellence-West, Veterans Health Administration
Veterans Affairs Puget Sound Health Care System, Seattle, WA
alicia.sloan@va.gov
MULTIPLE SCLEROSIS

CENTERS OF EXCELLENCE
“People expect to become caregivers for their children and parents. They do not expect to become caregivers for their spouse.”

(Courts, Newton, & McNeal, 2005)
“MS Caregivers” Defined

- “An individual who cares for a friend or family member through helping the care recipient with activities of daily living or instrumental activities of daily living.” (Multiple Sclerosis Caregivers Report, 2012)
- “An unpaid person who helps with the physical care or coping with the disease.” (Hileman, et al., 1992)
- “With MS, it is often a family member, a partner, parent or adult child.” (CMSC website: www.mscare.org/cmsc/News/Web-Sights-Caregivers-Stress-2.html)
- “Informal caregivers are the primary resource allowing people with MS to remain in their homes.” (Dunn, 2011)
What do Veterans with MS and Caregivers Need?

“It is important for those of us with MS to have a support team including friends and family members…”

“…In my own case, I have some great friends who understand my situation and offer tremendous physical and emotional support.”

~ Veteran with MS, www.va.gov/MS
History of MS Caregiving Research

1980: Caregiver Burden in chronic disease research began.

1997: (Aronson) First Quality of Life Study of people w/MS and their Caregivers
- CG has a poorer QOL if...
  - A spouse
  - Longer duration of caregiving
  - Moderate or worse MS symptoms
  - Unstable MS disease course
History of MS Caregiving Research

Dunn Lit Review (2011):

Good review of MS Caregiver Research over 20 years

- Reduces cost of outside paid caregiving
- ‘Hidden patient’ - physical, emotional, psychological, social and economic burdens (Buhse, 2008)
- 75% live with care recipient
- 42% sole caregiver
- Average duration = 9 years
- Loss of mobility = greater burden for caregiver
- May not be prepared for physical tasks
- Recommends caregiver training
- Health problems of MS patients mirrored in their caregivers.
History of MS Caregiving Research

- **Caregiver Therapeutic Interventions:** Caregivers should be targeted for focused therapeutic strategies (Pozzilli, 2004)
- **Respite/Palliative Care:** Reduces caregiver burden (Edmonds, 2010)
- **Family Systems/Young Caregivers:** Young caregivers affected positively and negatively by parents with MS (Pakenham, 2007, 2012)

**Latest on MS & Caregivers:**

- Multiple Sclerosis Caregivers Report, 2012
  - National Alliance for Caregiving
  - National MS Society
  - Southeastern Institute of Research
Who are the Caregivers of Veterans?

- 2010 VA Study: Caregivers of Veterans – Serving the Homefront Study
  - Quantitative online survey
  - 462 self-identified family caregivers, age 18 or older, who provide care to a veteran whose injury, illness, or condition is related to military service.
  - Influenced development of VA national Caregiver Program

## Caregiver Demographics

### Veteran vs. National Statistics

<table>
<thead>
<tr>
<th></th>
<th>Caregivers of Veterans (n = 462)</th>
<th>Caregivers of Adults Nationally (n = 1,307)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female caregiver</td>
<td>96%</td>
<td>65%</td>
</tr>
<tr>
<td>Spousal caregiver</td>
<td>70%</td>
<td>6%</td>
</tr>
<tr>
<td>Caregiver lives with care</td>
<td>80%</td>
<td>23%</td>
</tr>
<tr>
<td>recipient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary caregiver</td>
<td>82%</td>
<td>53%</td>
</tr>
<tr>
<td>Caregiving for 10 years</td>
<td>30%</td>
<td>15%</td>
</tr>
<tr>
<td>or more</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Caregivers of Veterans – Serving the Homefront Study, 2010)
Who are the Caregivers of Veterans?

- Spouse/partner: 70%
- Parent/parent-in-law: 16%
- Son or daughter: 9%
- Other: 5%

(n=462)

(Caregivers of Veterans – Serving the Homefront Study, 2010)
Who are the Caregivers of Veterans?

- Live in same household: 80%
- Live separately, in a residence: 15%
- Live separately, in a care facility: 5%

(n=462)

(Caregivers of Veterans – Serving the Homefront Study, 2010)
Who are MS Caregivers?

From 421 MS Caregiver Respondents:

- 40% Male
- 60% Female
- Average Age = 46
- 72% Married or living with partner
- 38% have Children under age 18
- 2/3 have College or Graduate degrees
- 70% Household Incomes were >$50,000/year
- Median Income for all respondents $79,000
- 58% Employed Full-Time

(Multiple Sclerosis Caregivers Report, 2012)
Who are MS Caregivers?

- 30% Spouse or Partner
- 26% Son Daughter
- 15% Other Relative
- 10% Sibling
- 7% Friend Neighbor
- 5% Parent

(Multiple Sclerosis Caregivers Report, 2012)
Impact of MS Caregiving on Relationships

Benefits and burdens of caregiving
• Strengthens relationships
• Loss of personal identity
• Limited support systems and resources

Areas MS Caregiver research is needed
• Services most helpful and necessary to support caregivers
• How couples cope with relationship changes
• Coping with transition of partner to caregiver
• Develop interventions to facilitate and support role changes and prevent relational strain

(Kraft, et al., 2008.)
Caregiving of MS
Did We Have a Choice?

- Almost half (48%) of respondents felt they did not have a choice in taking responsibility for caring for the person with MS.

(Multiple Sclerosis Caregivers Report 2012)
Caregiving of Veterans
Did We Have a Choice?

(n=462)

Don't know
4%

Yes
29%

No
67%

(Caregivers of Veterans – Serving the Homefront Study, 2010)

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Time Spent Caregiving

- 24 hours per week average spent caregiving
- 13% spend more than 40 hours per week caregiving
- Activities of Daily Living (ADLs) involved in caregiving
  - Bathing
  - Dressing
  - Feeding
  - Toileting, etc.
- Instrumental Activities of Daily Living (IADLs)
  - Shopping,
  - Housekeeping
  - Transporting to Doctor
  - Cooking
  - Handling Finances, etc.

(Multiple Sclerosis Caregivers Report 2012)
External help for caregivers

- 27% of Caregivers are the **only** caregiver

- Caregivers who have supplemental paid in-home care support spend the **same amount of time** providing care as those who do not

  (Multiple Sclerosis Caregivers Report 2012)
MS Caregiver Burden

MS Symptoms That Increase Burden on Caregivers

• Difficulty walking
• Cognitive Impairments
• Depression/anxiety
• Frequency of bladder dysfunction
• Instability of symptoms

Caregiver Health Problems

• Tiredness
• Depression
• Back pain
• Insomnia
• Shortness of breath

Notice how many Caregiver symptoms mirror the Care Recipient’s MS symptoms?

(Dunn, 2011; MS Caregivers Report, 2012)
MS Caregiver Burden

- Most commonly reported emotional responses by caregivers responding to initial MS diagnosis:
  - Compassion
  - Fear
  - Anxiety

- Negative impacts of caregiving reported:
  - Financial situation (43%)
  - Ability to participate in hobbies (39%)
  - Mental health (38%)

(Multiple Sclerosis Caregivers Report 2012)
MS Caregiver Burden

• 1/3 suffer depression because of providing care
• 1/2 are physically exhausted
• Nearly 1/3 have experienced physical injury as a result of caregiving
• 22% have lost a job due to caregiving
• 17% report not being able to hold down a job due to caregiving

(Multiple Sclerosis Caregivers Report, 2012)
Emotional Impact of Caregiving of Veteran

- You do not have enough time for yourself: 47% agree strongly, 36% agree somewhat, 84% total.
- You feel you don’t have a life of your own anymore: 41% agree strongly, 36% agree somewhat, 77% total.
- You feel no one else really understands what you’re going through: 39% agree strongly, 37% agree somewhat, 76% total.
- You feel isolated: 31% agree strongly, 41% agree somewhat, 72% total.
- You feel you are the only person who can provide adequate care to the veteran: 29% agree strongly, 37% agree somewhat, 66% total.
- You hesitate to take your veteran anywhere because you are afraid of what might happen: 23% agree strongly, 34% agree somewhat, 56% total.

(Caregivers of Veterans – Serving the Homefront Study, 2010)
Top Challenges Faced by Caregivers of Veterans

Each experienced by at least 2/3 Caregivers:

1. Not knowing what to expect medically with Veteran’s condition
2. Not being aware of Veterans Affairs (VA) services that could help
3. Not knowing how to address PTSD or mental illness
4. Difficulty getting through bureaucracies in order to obtain services
5. Not knowing where to obtain financial assistance
6. Not knowing where to turn to arrange a break from caregiving
7. Not knowing where to obtain specialized care
8. All but the first of these challenges are more commonly noted by caregivers of veterans who have TBI.

(Caregivers of Veterans – Serving the Homefront Study, 2010)
Stages of Readiness of Support

- Hard to ask for support
- Phases in Caregiver’s decision to seek and accept support
  1. Rejecting support
  2. Resisting support
  3. Seeking support
  4. Accepting support

How Helpful Are We To Caregivers of Veterans?

“How helpful has the care/case manager or social worker been in locating, arranging, and coordinating suitable care and resources?”

(Caregivers of Veterans – Serving the Homefront Study, Veterans Affairs)

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Social Work Roles

- Utilize traditional social work roles to assist Caregivers and Veterans
  - Strengths-based
  - “Person” and “Client” Centered
  - “Best Practice” models
  - Lead clients to a positive sense of self and interdependence

(Curtin, 2012)
Person-Centered Models

• Use with Caregivers
• Person-centered models and social work roles:
  ▪ Help alleviate caregiver burden/stress
  ▪ Create interdependence w/caregiver and care partner
  ▪ Encourage caregiver to share responsibilities
• Caregiver assessments (Zarit Burden Scale, etc.)
  ✓ Evaluate at baseline
  ✓ Re-evaluate after implementing model.
Veterans with MS

- 43,841 Veterans with MS
  - MSCOE National MS Repository

- Est. 6,000+ Veterans with MS receive care at VA
  (MSCOE, 2012)
Veterans with MS Perception of Caregiving:

- Male Veterans w/MS who are married or living with someone, and/or RRMS reported high level of support from their Caregiver. Higher than married women Veterans w/MS. (Williams, Turner, Haselkorn, et al., 2004)

- The greater perceived social support from Veteran with MS & perceive greater affectionate support from Caregiver, less depression in Veteran.
  - Men with MS report greater perceived social support and greater perceived emotional/information and tangible support compared to women with MS.
  
  (Bambara, Turner, Williams & Haselkorn, 2010)

Caregivers of Veterans w/MS

- “Supportive qualities” of Caregiver significant for better DMT adherence.
  
  (Siegel, Turner & Haselkorn, 2008)
Buchanan & Huang 2013 Caregiver Study

- 530 MS caregivers
- Care Recipients more functionally dependent (from NARCOMS, PDDS score of 5 through 8)
- Telephone interview
- 53.2% male caregivers, 59 years old
- 83% spouses/significant other caregivers, 12% family caregivers, 6% friend
- Caregivers with poorer mental health more likely to provide lower-quality care and assistance
- The more emotionally draining or felt assistance was affected the caregiver/care recipient relationship, increased need for mental health treatment
- Older caregiver: decreased need for mental health treatment
• Practice Points for Health Professionals
  ➢ Be sensitive to impact of caregiving has on emotions and mental health of caregivers
  ➢ Adapt internet and telephone support, therapy, education and training that reduce stress and improve mental health
  ➢ Administer caregiver self assessments
Margaret Kazmierski, MSW, LCSW-C, MSCS
Clinical Social Worker, Spinal Cord Injury Coordinator
MS Center of Excellence-East, Veterans Health Administration
VA Maryland Health Care System, Baltimore, MD
margaret.kazmierski@va.gov
THE VETERANS HEALTH ADMINISTRATION: FOCUS ON THE CAREGIVER
VA NATIONAL CAREGIVER PROGRAM

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VA NATIONAL CAREGIVER PROGRAM

CAREGIVER SUPPORT LINE
1-855-260-3274

SERVICES
FOR CAREGIVERS OF
POST-9/11 VETERANS
Click Here to Learn More

How can
we help you?
I need help with:
Make a selection ...

Find your local
Caregiver Support
Coordinator
Zip Code

Sign Up and Stay Informed
Sign up below to receive regular
e-mail updates about VA
Caregiver Support.

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Everyday Tips and Checklists

We know you juggle a lot of big responsibilities every day. We also know that sometimes you may feel like the little things – or the things you should do for your own well being – are slipping through the cracks.

For those times, an easy checklist or tip sheet can be the best tool in your tool box. The tools below can help you stay on track so you can stay focused and feel in control.

**Patient File Checklist (PDF)**
The single most important thing you can do to promote clear communication and function effectively as a Family Caregiver is to create and maintain a comprehensive file of information about the Veteran you’re caring for. Follow the link for more information and a checklist that will help you build a comprehensive file about the Veteran you care for.

**Tips for Communicating with Your Veteran’s Health Care Team (PDF)**
As a Family Caregiver, it’s important to be aware of all aspects of a Veteran’s health care. That means being able to communicate effectively with a Veteran’s health care team. Download this PDF for tips on maintaining productive, effective communication with the health care team providing treatment for the Veteran you love.

**Questions to Ask Your Veteran’s Health Care Providers (PDF)**
All too often we don’t know what to ask the doctor about our own health, let alone someone else’s. Asking the right questions and getting the right answers from the health care team providing treatment for the Veteran you love will enable you to better plan for and provide care for that Veteran. Download this PDF for a list of common questions you may want to ask the clinical health care providers.
Caring for the Caregiver

Practical ways to help yourself as a caregiver

Caring for a Veteran with an illness, injury or disability can be stressful and exhausting. These tips can help you find the support you need.

1. Ask for help.
   - Ask a friend to fix dinner, or a relative to help out for an hour each week.
   - Make a list of ways others can help. When a friend asks, “What can I do?” have them choose from the list.
   - Don’t wait for a crisis. Ask for and accept help on a regular basis.
   - Even if asking is hard, find at least one resource you can use right away.

2. Express your feelings.
   - Recognize that feelings of frustration, sadness, anger and depression are normal under the circumstances.
   - Talk about your feelings with a friend, relative, counselor or caregiver support group.

3. Take care of your health.
   - Make sure you are eating a healthy diet, getting regular physical activity, and getting plenty of rest.
   - Learn and use stress reduction techniques.
   - Don’t put off your own medical care. Talk with your doctor about getting flu shots and other preventive care.

4. Learn about the disease.
   - Find out about the illness, injury or disability so that you are not taken by surprise when new situations occur.
   - If you can, provide information to family and friends so they will know how best to support you.

5. Avoid isolation.
   - Pursue a hobby or take a class. Join a reading or discussion group.
   - Become active in a community organization.
## Multiple Sclerosis Centers of Excellence

### Stories About Living with MS

As a former Air Force medic “Jersey” Jeanne writes about her life as an athlete and now as an adaptive athlete. Sports is a life-changer and helps her cope with secondary progressive MS in a positive way. [More]

You can read more Veteran Stories, participate in Monthly Calls, see Educational Videos and order FREE DVDs.

### MS Diagnosis

- **VA provides health care services to veterans with MS whether or not they have a service-connected disability from the time of diagnosis throughout the Veterans life.** [More]

### MS Therapies

- **Disease modifying therapies** have dramatically improved the treatment of MS. Read about them, and the [Multiple Sclerosis Emerging Therapies Collaborative].

### Symptom Management

- MS is associated with a variety of symptoms and clinical signs. Read [Keep Cool](#) in our section devoted to Symptom Management [More]

### Living with MS

- MS and MS impairments can limit some activities and social participation. A person’s mobility can be restricted. It may be difficult to walk, drive, push a wheelchair, and perform tasks on your own. [More]
Caregivers / Care Partners - Taking Care of Yourselves!

Caregivers and Care Partners are very important to our Veterans with MS. Be sure to take care of yourself too as you care for your loved one with MS. If you aren’t healthy, it’s harder to provide good care.

The website links below give tips on well deserved respite time (taking a break!). All Veterans and Caregivers are eligible for 30 days of respite time per year.

If you need to talk to someone about caregiving, call the VA Caregiver Support Line at (855) 260-3274. A Caregiver coordinator can tell you about benefits for you and your Veteran with MS.

- VA Respite Care
- VA Caregiver Support Website
- VA Caregiver Website Toolbox
- VA Caregiver Workbook
- National MS Society - A Guide for Caregivers
- Paralyzed Veterans of America

MS Caregivers - News and Articles

Emotional Changes in the Veteran with Multiple Sclerosis (MS): Tips for the MS Caregiver

By Margaret Kazmerski, MSW, LCSW-C, MSCS and Alicia Sloan, MPH, MSW, LICSW

Many people diagnosed with MS say that the emotional changes are some of the most challenging symptoms to cope with. This can have a profound emotional effect on the Caregiver. If you understand how MS affects your loved one emotionally it may help you as you cope with your own feelings and the stress and challenges in your role as a Caregiver. > Read the article

Monthly Caregiver Calls

Please join us on monthly MS Caregiver conference calls! Calls are sponsored by the MS Centers of Excellence. Each month we discuss different topics to assist caregivers.

Who
Families and Caregivers of people with MS

When
4th Monday of every month

January 28
February 25
March 25
April 22
May 27
June 24
July 22
August 26
September 23
October 28
November 25
December 23

Time
Pacific Time: 11am - 12 noon
Mountain Time: 12 - 1 pm
Central Time: 1 - 2 pm
Eastern Time: 2 - 3 pm

How
Call 1 (800) 767-1750, then punch in 43157#

Presenters & Facilitators
Monthly Caregiver Calls

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Presenters & Facilitators

Maggie Kazmierski (MSW, LCSW-C, MCS)

Alicia Sloan (MPH, MSW, LICSW)

Presentations for the call
April 22, 2013 Call Presentation
Travel and Recreation
VA MS Caregivers: Improving Opportunities for Communication

- **Veteran Centered Care**
  - Provider/Caregiver listens to needs and concerns of Veteran
  - Caregiver/partner key role

- **Institute of Medicine (IOM) Research found:**
  - Communication = Better Outcomes
  - Fewer Medical Errors
  - Better patient and Caregiver satisfaction
  - Better adherence to TREATMENT PLANS
  - Fewer medical malpractice suits
MSCOE National MS Caregiver Education & Support

• **Monthly Caregiver Call:** MS Social Worker Facilitated
  • Average # Calling In = 15
  • Range = 1-50

**Conference Calls:** 4th Monday of every month
**Time:** 11am-12noon PT, 12-1pm MT, 1-2pm CT, 2-3pm ET
**How:** Call 1.800.767.1750, code 43157#

[www.va.gov/MS/articles/Education/Free_Monthly_Educational_Conference_Calls.asp](http://www.va.gov/MS/articles/Education/Free_Monthly_Educational_Conference_Calls.asp)

• **MSCOE Caregiver Webpage:** [http://www.va.gov/MS/multiple-sclerosis-caregivers-home.asp](http://www.va.gov/MS/multiple-sclerosis-caregivers-home.asp)

• **Stories:** [www.va.gov/MS/Family_is_Everything.asp](http://www.va.gov/MS/Family_is_Everything.asp)

• **Newsletter:** [www.va.gov/MS/Newsletters.asp](http://www.va.gov/MS/Newsletters.asp)
MULTIPLE SCLEROSIS
FAMILY & CAREGIVER
CONFERENCE CALL

WHEN:  4th Monday of Each Month
TIME:  2-3 pm ET, 1-2 pm CT,
       12-1 pm MT, 11-12 am PT
DIAL:  1-800-767-1750, Enter Access Code 43157 and Press #

FOR INFORMATION CONTACT:
Alicia Sloan, MPII, MSW, LICSW
Alicia.Sloan@va.gov or 800-329-8387, 63598
Maggie Kazmierski, LCSW-C, MSACS
Margaret.Kazmierski@va.gov or 800-462-6295, 5095
MSCOE Caregiver Call
Educational Topics

• Laugh out Loud! Laughter for Caregiver Wellness
• How to talk to your MS Provider
• Caregiver Communication Strategies
• Caregiver Stress Management
• Sharing Caregiving Stories
• Caregiver Research
• Caregiver Respite
• Travel and Recreation with MS

www.va.gov/MS/articles/caregiver_presentations.asp
Resources

VHA Resources
- VA Caregiver support line: (855) 260-3274
- VA Caregiver Support: www.caregiver.va.gov
- VA MS Centers of Excellence (MSCoE): www.va.gov/ms

MS – Specific Resources:
- MS International Federation: www.msif.org/en/life_with_ms/family_friends_and_carers
- CMSC: www.mscare.org/cmsc/News/Web-Sights-Caregivers-Stress-2.html
  www.mscare.org/cmsc/News/Web-Sights-MS-Caregivers.html
- National MS Society:
Caregiver Assessment Tools

- Zarit Burden Scale (Zarit, 1980)
  www.aafp.org/afp/20001215/2613.html

- Caregiver Strain Index (CSI) (Robinson, 1983)
  www.npcrc.org/usr_doc/adhoc/caregiver/Caregiver%20Strain%20Index.pdf

- Caregiving Tasks in MS Scale (CTiMSS) (Pakenham, 2007)
  • Email Dr. Ken Pakenham: kenp@psy.uq.edu.au

- Caregiver Reaction Assessment Scale (CRA) (Given et al., 1992)
  • Email Dr. Barbara Given, Michigan State University. barb.given@hc.msu.edu

- CAREQOL-MS: Caregiver Quality of Life (Benito-Leon, 2011)
  www.sciencedirect.com/science/article/pii/S0895435610002866
Note: To connect directly to websites listed, make sure you are in “Slide Show” view and hover mouse over hyperlink and click.

Presentation References

Presentation References

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- For continuing education credit for this activity please visit:

  www.pesgce.com/PVA2012
Thank you