BEST PRACTICES: Caregiver Support

Paul McDonough, MSW, LCSW
Senior Social Worker
Social Work Service
VA Long Beach Healthcare System, CA

Alicia Sloan, MPH, MSW, LCSW
Clinical Research Coordinator
VA MS Center of Excellence – West
VA Puget Sound Healthcare System
Seattle, WA

Marguerite Allen-Wooten, MSW, LCSW-C, M Ed
SCI/D Program Manager
Social Work Service
VA Medical Center, Washington, D.C.

Marsha Tarver, PhD (Moderator)
Associate Director of Education
VA MS Center of Excellence - West
VA Puget Sound Healthcare System
Seattle, WA

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Orlando, FL
Learning Objectives

At the conclusion of this activity, the participant will be able to:

1. Define “caregiver” & provide a clear picture of the challenges & needs of caregivers of our Veterans.

2. Discuss current caregiver support “best practices” & policies.

3. Review current VA practices & research that address caregiver support for our Veterans with SCI & MS.
Disclosures

- All speakers have no financial interest or relationships to disclose.
- CME Staff Disclosures: Professional Education Services Group staff have no financial interest or relationships to disclose.
Disclosures Continued

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Who Are Our Caregivers?

Paul McDonough, MSW, LCSW
Senior Social Worker
Social Work Service
VA Long Beach Healthcare System, CA
September 16th, 2011
Different Veterans / Different Needs

- WWII
- Korea
- Vietnam
- Gulf War “1”
- OEF/OIF/OND

McDonough, 8/16/11
### 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 recipient</td>
<td>80%</td>
<td>23%</td>
</tr>
<tr>
<td>Primary caregiver</td>
<td>82%</td>
<td>53%</td>
</tr>
<tr>
<td>Caregiving for 10 years or more</td>
<td>30%</td>
<td>15%</td>
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</tbody>
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## Caregiver Demographics

### Veteran vs. National Statistics

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</thead>
<tbody>
<tr>
<td>High Emotional Stress (4+ on 5-point scale)</td>
<td>68%</td>
<td>31%</td>
</tr>
<tr>
<td>High Physical Strain (4+ on 5-point scale)</td>
<td>40%</td>
<td>14%</td>
</tr>
<tr>
<td>Stopped working or took early retirement (among those who worked while caregiving)</td>
<td>47%</td>
<td>9%</td>
</tr>
<tr>
<td>High Financial Hardship (4+ on 5-point scale)</td>
<td>50%</td>
<td>13%</td>
</tr>
</tbody>
</table>

Caregiving Strengths

- Improved relationship with care recipient & family.
- Improved sense of self-worth.
- **Note:** It is essential for person providing care to label themselves as a “caregiver” to receive proper support.
Caregiving Challenges

- Increased stress / anxiety
- Sleep deprivation
- Decreased self-care behaviors
  - Healthy eating
  - Exercise
  - Routine health & dental/vision care
- Financial difficulties
  - Loss / decreased abilities
  - Loss / decreased time to work
- Poor health
- Death
- **Note:** Isolation & lack of support are primary factors in exacerbating these challenges.
National VA Programs

• Fee-Basis/Contract /In-Home Programs:
  ➢ Adult Day Healthcare
  ➢ Home Based Primary Care
  ➢ Skilled Home Care (Visiting Nurse)
  ➢ Homemaker/Home Health Aid
  ➢ Home Telehealth
  ➢ Respite Care
  ➢ Home Hospice Care

• Caregiver support line: (855) 260-3274
• Caregiver support website: www.caregiver.va.gov
• Caregiver support coordinators
New to caregiving?
VA is here to help.

VA is here to help. Our New to Caregiving section can help you get your bearings as you adapt to your new role. Learn More

Wanda's Story
When anticipating retirement and growing old together, Wanda had never pictured her active and able husband being physically bound to his bed. Bob, a Veteran of the U.S. Army, who served during World War II, wanted nothing more than to stay in his home, despite his life-altering condition.

Staying Organized
Medication Log
A medication log can help you keep track of a Veteran's prescription and over-the-counter medications, when they should be taken, and what's working (and what isn't).

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.

Download PDF Reader
As a Family Caregiver, you know better than anyone else that caring for a Veteran requires major organizational skills. Whether you are new to family caregiving or looking for fresh tips and resources, VA has created this Caregiver Tool Box to help you find tools that work for you. This page offers resources and information to help you stay on top of things and manage the daily stresses of family caregiving.

**New To Caregiving**

Have you recently become a Family Caregiver of a Veteran? Feeling overwhelmed? This section provides tools and information to help you learn what to expect as a Family Caregiver and how to balance your new responsibilities.

**Diagnosis Care Sheets**

You’re not a doctor, but you’ve taken on the responsibility of providing specialized care to the Veteran you love. To help support your caregiving efforts, this section provides care sheets to help you better understand common diagnosis and tips for managing your Veteran’s care at home.

**Everyday Tips and Checklists**

A checklist can be a great tool for helping you keep track of what you need to do and reminding you what still needs to be done. To support your caregiving efforts, VA has created checklists for new Family Caregivers, questions to ask the doctor, and other information to help you. Click here to learn more.
Staying STRONG

Taking care of the Veteran you love is often your primary focus for the day. But sometimes, staying strong for that Veteran and your family can feel exhausting, and leave you without much time for yourself.

VA can help. Visit the links below for information and tips to help you stay strong and stay informed. After all, your health is essential to your ability to keep providing for the Veteran you love.

Maintaining Balance

Balancing caregiving, family and work can be both rewarding and challenging. You are juggling many different responsibilities, and VA understands that. In this section, find tips for creating balance in your life and keeping yourself healthy - get tips about how to ask for help when you need it, learn ways to help yourself feel focused and fully charged, and find joy in the small pleasures while caring for the Veteran you love. Remember, VA is here for you, too.

Caring for Yourself

Have you ever had one of those days when you had to ask yourself, “Did I brush my teeth today?” It’s a simple task, but an important one, and it’s easy to forget about it when you’re putting the Veteran you
Preventing Medication Mishaps

Following these simple rules can help you prevent problems caused by interactions between medications, vitamins, supplements, and foods. It is one more way that you can be a good steward of a Veteran’s health. It is also a good example of what it means to be a proactive Family Caregiver.

While you are following these steps to protect the Veteran’s health, consider following them for yourself as well. Remember, your own good health is essential to your being an effective Family Caregiver.

1. Maintain an Up-to-date List

First and foremost, maintain an up-to-date list of everything the Veteran takes. List medications prescribed by doctors, but also list those purchased without a prescription such as aspirin, vitamins, and herbal supplements. These over-the-counter items can at times interact with prescription drugs and create serious problems. You are probably the only one who knows all the medications the Veteran is taking, especially if he/she sees multiple physicians.

• Be sure to list the name, dosage, and frequency of the medication (e.g., Warfarin 4mg, once a day), the reason for taking it (blood clot prevention), any dosing
National Program Specific to SCI/D

- Annual Psychosocial Assessment
- Fee-Basis: Bowel and Bladder
- **30 days!** Respite Care
- SCI/D Home Care
  - Home Based Primary Care utilizing SCI Staff

- Policy
  - VHA SCI/D Handbook 1176
  - **New!** VHA Multiple Sclerosis SOC Handbook 1011.06

McDonough, 8/16/11
Homework

- **Visit!** [www.caregiver.va.gov](http://www.caregiver.va.gov)
- **Identify!** Name and contact information of your Caregiver Support Coordinator.
  - Call and ask about local programs and referrals.
- **Develop!** 1-page resource list for the caregivers of your specific Veterans.
  - Make it easily available.
Caregivers Wear Many Hats!
Caregiver Research: Implementation to Social Work Practice

Alicia Sloan, MPH, MSW, LCSW
Clinical Research Coordinator
VA MS Center of Excellence – West
VA Puget Sound Healthcare System
Seattle, Washington
MS/SCI Caregiver Studies

- The Hidden Patient: “The n of 2!”
- Caregivers Accepting Help
- Caregivers Seeking Help
- Caregiver Burden/Stress
- Caregiver Quality of Life
- MSCoE Specific Studies
- SCI Specific Studies
Literature Search Results

PubMed Key Words:

- caregiver, spinal cord, veterans = 9
- caregiver, multiple sclerosis, veterans = 2
  - Both publications from VA Puget Sound/MSCOE
- caregiver, veterans = 426
Informal Caregivers: Unique Challenges

Caregivers - “The Hidden Patient”

- MS Caregiver burden research only 20 years old.
  - 697 Respondents with MS, 345 Caregivers.
- Caregiving reduces need for paid healthcare services outside home.
- Loss of mobility, greater need for CG helping ADLs. CGs may not be prepared for physical tasks required.

Social Worker Tips!

- Early recognition & treatment of CG burden important.
- Listening, noticing changes in behavior of CG.
- CG Burden & Stress Assessments.
- Training CGs.

Caregiver Assessment Scales

- Sullivan Lit. review of 9 CG assessments. Likes CSI: short, easy, objective.
- Zarit Burden Scale (Zarit, 1980)
- Caregiver Strain Index (CSI) (Robinson, 1983)
- CAREQOL-MS: Caregiver quality of life (Benito-Leon, 2011)
- Caregiving Tasks in MS Scale (CTiMSS) (Pakenham, 2007)
- Caregiver Reaction Assessment Scale (Forbes, 2007) w/SF-36
  - 257 MS CGs survey of subjective/objective/dyadic dimensions of caregiving.

Social Worker Tips!
- Use these tools to assess and monitor CG burden & stress.

Sloan, 8/16/11
Caregivers “Seeking” Help

- 70% Depend on “word-of-mouth” for help
- 66% Turn to VA/VBA
- 60% Turn to non-VA provider
- 48% Turn to professionals, support groups; Online resources, forums, groups or blogs.
- 39% Turn to disease-specific organizations, in-person support groups.
- CGs of younger Veterans: Turn to Online resources, Department of Defense military system and Military OneSource.
- CGs of older Veterans: Turn to local government or community organizations.

Social Worker Tips!

- Know your Veteran population & reach out to their CGs.
- Consider different types of resources for CGs of older vs. younger Veterans.
- What is accessible to the older/younger caregiver.

Caregiver “Accepting” Help

Phases in caregiver’s decision to seek and accept support:
1. Rejecting support
2. Resisting support
3. Seeking support
4. Accepting support

Social Worker Tips!
- Identify phase caregiver is currently experiencing.
- What do you notice?
- What makes the most sense for support?
- How can you help CG with the changing phases over time?

Caregiver Quality of Life

- Being a Spouse
  - Wife CG more likely to develop clinical depression than husband CG.
  - MS Diagnosis & disease progression affects newly married/coupled partners: economic/social burden, financial strain, disease uncertainty, disrupted usual activities.
- Longer duration of caregiving
- # Hours per Week providing assistance
- Extent to which responsibilities restrict personal activities
- Palliative care service (Respite) can help key MS symptoms & reduce caregiver burden.

**Social Worker Tips!**
- Look for signs of depression in Caregiver, especially with women.
- Discuss financial assistance & future plan.
- Discuss respite/palliative care & additional home based care benefits w/ Caregiver
- Identify Caregiver’s important activities & develop activity plan!

MS Caregiver Burden

Buchanan Study:
• National survey: Focused on MS male caregivers

Results:
➢ Greater burden assoc. greater hours per week providing assistance.
➢ Strong assoc. between perception of burden & mental health status of male CG

Social Worker Tips!
• Pay attention to gender differences & caregiver stress/burden.
• Share research information with male CG. He may be more responsive to accepting support.
• Offer respite care services, support groups.

Sources: Buchanan, et al. 2011.
Caregiver Burden & MS Specific Symptoms

Dunn 2011 Lit Review

- Specific symptoms in MS patients contribute more to MS CG burden.
  - Difficulty walking
  - Memory loss
  - Depression/anxiety
  - Frequency of bladder dysfunction
  - Moderate or worse MS symptoms
  - Other Health Problems: tiredness, depression, back pain, insomnia, shortness of breath, sexual & relationship problems.

**Social Worker Tips!**

- Pay attention to Veteran minimizing need for caregiver care.
- Are mobility issues being addressed by MS Care Team?
- Is a bladder management program needed?
- Has cognitive testing occurred or need to be repeated?
- Is the Veteran seeing a MH provider?
- Has Veteran been evaluated for depression?
- Would a support group be helpful?
- Does the MS Care Team know about current MS symptoms?
MSCoE Research

Address special health care needs of Veterans with MS.

- Higher proportion of males w/MS
- More disabled
- Higher % of progressive forms of MS

Research: Patterns, correlations, and/or effectiveness of an intervention or medication for management of MS symptoms.

Source: MS Centers of Excellence.
MSCOE Study #1: Social Support

Caregivers Providing Social Support to Veteran with MS
- Veterans perceived social support.
- Gender differences in relationships.

Results:
- Male, married, living with someone, and/or relapsing-remitting MS reported greater social support.
- Married men reported higher levels of 4 of 5 types of support than married women.
- Higher income was associated with greater total social support for women.

Social Worker Tips!
- Provide interventions tailored by gender and marital status.
- Pay particular attention to male married caregivers: Are they getting the support they need as a caregiver?

MSCOE Study #2: Social Support and Depression

DMT Study with Veterans & their Caregivers

• Veteran Adherence to MS DMT.

Results:

• Less depression in Veterans w/MS = Greater ...
  ➢ Global perceived social support.
  ➢ Veteran’s perceived emotional/informational support.
  ➢ More positive social interactions.

Social Worker Tips!

• Provide Caregiver education & training emphasizing emotional & affectionate support.
• Be perceptive of marital strife: Refer to communications training/relationships counseling if needed.


Sloan, 8/16/11
MSCOE Study #3: Veterans DMT Adherence

DMT Study with Veterans & their Caregivers
- 54 Veterans with MS who identified a caregiver.
- 85% male Veterans.
- Over 80% caregivers are spouses.
  - Not in paper: Another aspect of Study: Telehealth monitoring of DMT adherence

Results: Caregivers are important for medication adherence!
- Veterans 85% adherence to DMTs. Caregivers & veterans very satisfied w/telehealth.
  - Comforting to CGs someone at other end monitoring.
- “Quality of Relationships Inventory” – To what degree is caregiver willing to listen, provide advice, help with a problem.
- “Supportive qualities” of caregiver significant for DMT adherence.

Social Worker Tips!
- Provide or refer Caregiver to training for MS DMT management.
- Mediset training; Medication diary
- Be familiar w/telehealth program: CCHT. How can you integrate into your practice
- DMT schedule, side effects / injection training.

Sloan, 8/16/11
SCI Study #1: Caregiver Profile

Profile of Veterans w/SCI & Caregivers

Results:
- 37% Veterans have Informal Caregivers
- Caregivers mostly women, average age 53.
- Caregivers = average 12 hours a day.
- 1/3 Veterans rated primary caregiver “fair or poor" health.
- 1/4 Veterans think caregiver unlikely to be able to provide same level of care in 5 years.
- >50% Veterans reported: No one else willing/able to provide assistance if primary family caregiver became unable to care for them.

Social Worker Tips!
- Respite care
- Long term plan for care support
- Caregiver support groups, in-person/telephone/web
- Caregiver assessment
- Compensation and pension planning
- Aid and attendance grants
- Home based care eligibility

Source: Robinson-Whelen & Rintala, 2003. Sloan, 8/16/11
SCI Study #2: Level of Disability & Caregiver Hours

Large Veterans survey & VA databases established national registry of Veterans w/SCI/D.

- Validated Self-Reported Functional Measure
- Clinical epidemiology of Veterans with spinal cord dysfunction.
- Identifies hours of Caregiving received previous 2 weeks.

Results:
- Strong relationship: self-reported disability & CG hours

Social Worker Tips!
- Pay attention to Veteran’s disability level and # CG hours.
- Does CG need respite care?
- What is long term plan for Caregiving?
- Useful information for compensation & pension applications.
- Data for justifications for benefits

SCI Study #3: Equipment Satisfaction

Satisfaction Questionnaire of Veterans & Caregivers

- Prone cart, stand-up cart, commode-shower chair used in SCI Centers.

Results:

- CGs / Veterans influenced improvement of new, self-propelled chair.
- 54% satisfied with design / usability
  1) Falls during transfers, propelling, leaning over for showering
  2) Pressure ulcers
  3) Positioning chair over toilet.

Social Worker Tips!

- Be on alert for falls risks.
- Listen to/ask Caregiver for reviews re: equipment.
- Work with MS Care Team for effective/efficient home equipment, safe transfers, skin breakdown, toileting & other ADLs.

Local Efforts in Caregiver Support

Group Discussion
“Powerful Tools for Caregivers”
- Peer or professional led groups
- Scripted, step-by-step program
- Room available: coffee, snacks, & internet access
- 1 - page biblio-support
- Treatment team meetings as needed
93 Veterans in program
20% receive monthly stipend

Caregivers

- 70% Spouses
- 20% Adult Children
- 10% Siblings, Other

Allen-Wooten, 8/16/11
MS Centers of Excellence

- Monthly National Caregiver Education & Support VANTS Conference Calls
- MSCOE Website: www.va.gov/ms
  - Living with MS – caregiver wellness
  - Web links to: www.caregiver.va.gov
- Books, DVDs, Pamphlets
- In Development:
  - SW led Caregiver support group (starts next month)
    - Caregiver Education Series (From pilot model of MSCOE)
  - MS home telehealth monitoring w/Care Coordination Home Telehealth (CCHT) w/Zarit Burden Scale of Caregivers.
Annual Conference for Caregivers (20 years!)
Provides information, education, support and a chance to meet others facing similar challenges as Caregivers.
Attendees: family members, friends and community health care professionals caring for adults with chronic illness and/or disability.
MSCoE participates in conference.
Founded by Taylene Watson, MSCW, LICSW, Director of Social Work; Coordinated by Kris Fredrickson, MSW, LISCW, Caregiver Coordinator.
Small Group Discussions

- What are you doing to help provide caregiver support?
- SHARE IDEAS!
- 2-3 groups will share what they discussed.
Managing and Reducing Stress

Social and Emotional

Marguerite Allen-Wooten, MSW, LCSW-C, M Ed
SCI/D Program Manager
Social Work Service
VA Medical Center, Washington, D.C.
The Three Universal Stages of Stress

- ALARM
- RESISTANCE
- EXHAUSTION
How can you assist Caregivers in Managing and Reducing Stress in their LIVES?
Encourage Caregivers to Spend Time Alone

Help them to:

- Learn how to slow down!
- Practice sitting quietly
- Listen to their inner voice
- Think about things which bring peace, beauty and serenity to their life.
Inspire Caregivers to Take Time to Exercise

Discuss options like:
- Go for a walk
- Remember to “break a sweat”
- Ride a bike
- Take the stairs
- Stretch muscles before & after exercise
Support Caregivers to Develop Healthy Eating Habits

Provide tools so they can

- Plan nutritious meals
- Prepare healthy snacks
- Stop overindulging
- Limit alcohol/nicotine, caffeine, sweets
- Enjoy meal time
Offer Ideas on Healthy Sleep Habits

Discuss Sleep Strategies

- 7 – 8 Hours of Sleep at Night
- Take a Nap during the Day
- Prepare Ahead for Sleep
Encourage Caregivers to Make Time for Social Contacts

Explain How To:
- Prepare in Advance for an Outing
- Take Time to Play
- Surround Self with Happy People
- Form a Small Group of Friends
Give Caregivers Permission to Ask for Help

Help CG to Appreciate the Value of:

- Calling on Friends & Relatives
- Making a List of Tasks
- Utilizing Respite Care
- Seeking Professional Support
Teach Caregivers How to Accept Assistance

Describe Practical Ways for CGs to Accept Help by:

- Preparing a List of Ways Others Can Help
- Allowing Others Who Help to Choose a Task
- Explaining How Not To Feel Guilty
- Remembering To Express Gratitude
Inspire Caregivers to Embrace the Joy of Laughter

Discuss the Value of:

- Accepting All Feelings - Positive and Negative
- Laughing at Yourself
- Looking for the Humor in Things around You
- Doing Something Silly and Unexpected
CAREGIVER AFFIRMATION

I will have time, alone.
I will take time to exercise.
I will eat healthy meals.
I will get sufficient sleep.
I will make time for social contacts.
I will ask for help.
I will accept assistance.
I will embrace the joy of LAUGHTER!

I am a CAREGIVER, Yes I am!

I am a spouse, parent, family member, and friend. I am determined to enjoy this journey, until the end!

I laugh, I soar, I beam, I shout with joy. When I feel like a kid with a new toy!

I have challenges, sometimes, by the hour. When I feel like giving up and throwing in the towel!

I say to myself, I am a CAREGIVER. I will continue to deliver!

This day, however; I will celebrate MYSELF. The beautiful soul that I am, at my best!

Yes, I will laugh and I will cry. But, I will remember that I am I!

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Questions/Contacts

- Paul McDonough, MSW, LCSW
  paul.mcdonough@va.gov
- Alicia Sloan, MPH, MSW, LICSW
  alicia.sloan@va.gov
- Marguerite Allen-Wooten, MSW, LCSW-C, M Ed
  marguerite.allen-wooten@va.gov
Resources

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

Community Resources
- Paralyzed Veterans of America: www.pva.org
- The National Alliance for Caregiving: www.caregiving.org
- National MS Society: www.nationalmssociety.org/living-with-multiple-sclerosis/relationships
- MS International Federation: www.msif.org/en/life_with_ms/family_friends_and_carers
- Today’s Caregiver Magazine: www.caregiver.com
- National Family Caregivers Association: www.nfcacares.org
- A caregiver managed website: www.caregiverscommunity.com
References

- Contact alicia.sloan@va.gov for full research references.
Obtaining CME Credit

• If you would like to receive CME credit for this activity, please visit:

  http://www.pesgce.com/PVAsummit2011/

• This information can also be found in the Summit 2011 Program on page 8.