

Reaching Out to Caregivers!

Increasing Access to Caregiver Support and Education: Unique Modalities for Multiple Sclerosis



**PVA Summit
September 3, 2015
Jacksonville, FL**

Presenters

❖ **Alicia 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

Disclosures

Alicia P. Sloan, MPH, MSW, LICSW

- Has no financial interest to disclose.

Margaret Kazmierski, MSW, LCSW-C, MSCS

- Has no financial interest to disclose.

This continuing education activity is managed and accredited by Professional Education Services Group (PESG) in cooperation with Paralyzed Veterans of America (PVA). Neither PESG, PVA, nor any accrediting organization supports or endorses any product or service mentioned in this activity.

PESG and PVA staff has no financial interest to disclose.

Commercial Support was not received for this activity.

Learning Objectives

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

1. Explain how more advanced MS can increase a caregiver's stress, depression, and general health problems.
2. Describe at least 3 modifiable risk factors contributing to caregiver well-being.
3. Discuss how telephone- and web-based modalities can increase access to resources and care for Caregivers.
4. Describe features of the evidence-based REACH MS program can help in clinical practice.
5. Discuss how social workers and providers working with MS Caregivers can increase access to educational resources and support.

Overview of Presentation



- ❖ Let's discuss the **Facts on Caregiving**
 - ✓ What do we know?
 - ✓ Research and Literature Review

- ❖ Let's discuss how to **Apply What We Know** to our clinical work
 - ✓ What modalities can work to increase caregiver support?

- ❖ Let's discuss how **We Can All Try** these modalities in our own health care setting
 - ✓ Small group activity
 - ✓ Let's plan it out!

Caregivers



"And do you take Goldie, to be your lawfully wedded primary caregiver?"

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

(Courts, Newton, & McNeal, 2005)

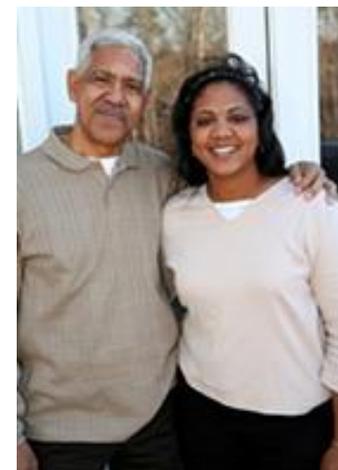
“MS Caregivers” Defined

- “With MS, it is often a family member, a partner, parent or adult child.”

(CMSC website: www.mscares.org/cmssc/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 Caregivers Need?



Bing Images

- “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, National Director of Social Work, and Heather Mahoney-Gleason, LICSW, National Caregiver Support Program Manager, 2010)

What do Caregivers Need?



Bing Images

“Compounding the pressure on caregivers is the feeling of guilt they often experience about doing something for themselves. They seem to need “permission” to take care of themselves and take advantage of available programs and resources.”

(Holland, Schneider, Rapp, and Kalb, 2011)

What do Veterans with MS and Caregivers Need?

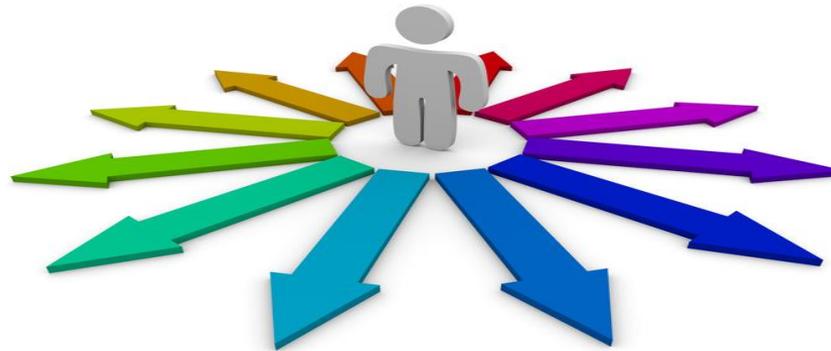


“It is important for those of us with MS to have a support team including friends and family members...”

~ Veteran with MS, www.va.gov/MS

Bottom Line!

FOCUS ON THE CAREGIVER



History of MS Caregiving Research

1980: Caregiver Burden in chronic disease research began.

1992: MS Caregiver Studies started (PubMed): Nursing research

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

2004: Caregiver Therapeutic Interventions (Pozzilli)

2007: Family Systems/Young Caregivers (Pakenham)

2008: “Hidden Patient” (Buhse)

2010: Respite/Palliative Care (Edmonds)

2011: Dunn Lit Review: MS Caregiver Research over 20 years

- Caregiving reduces cost
- Loss of mobility = greater burden for caregiver

2012: Multiple Sclerosis Caregivers Report

- ✓ The National Alliance for Caregiving
- ✓ National Multiple Sclerosis Society
- ✓ Southeastern Institute of Research, Inc.

2013: Buchanan & Huang Caregiver Study

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

MSCoE Caregiver Research

Veterans with MS Perception of Caregiving

- ❖ Male Veterans w/MS
- ❖ married or living with someone
- ❖ RRMS
- ❖ Reported high level of support from their Caregiver
- ❖ Higher than married women Veterans w/MS

(Williams, Turner, Haselkorn, et al., 2004)



MSCoE Caregiver Research

Caregiver Effects on Veteran

- ❖ Greater perceived social & affectionate support from Caregiver = less depression in Veteran.

(Bambara, Turner, Williams & Haselkorn, 2010)

- ❖ “Supportive qualities” of Caregiver significant for better DMT adherence.

(Siegel, Turner & Haselkorn, 2008)



Who are the Caregivers of Veterans?

- 96% - Female
- 80% - Live in the Same Household as Veteran
- 70% - Spouses or Partners
- 30% - 10+ years as Caregiver

(2010 VA Study: Caregivers of Veterans – Serving the Homefront Study)



Risk Factors of CG Burden/Strain

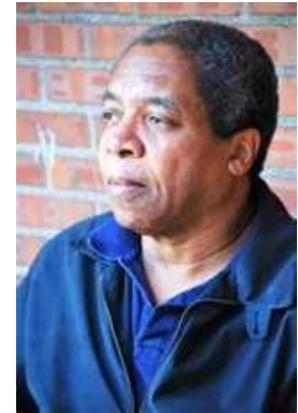
- Female
- Lower education level
- Living with care recipient
- Social isolation, support, relationships
- Marital relationships
- Financial stress
- Higher number of hours spent caregiving
- Lack of choice in being a caregiver



(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)

Risk Factors of CG Burden/Strain

- Quality of Life
- Self-esteem/Self-efficacy
- Mental or emotional strain:
 - Depression
 - Anxiety
- 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)

VA Major Areas of Focus of Caregiver Support



1. Respite Care
2. Education
3. Training
4. VA Supportive Services: HBPC, ADHC, H/HHA, Prosthetics, Travel, home grants, etc.
5. Community Resources, VA Partners
6. Caregiver Wellness
7. Emotional And Spiritual Health
8. Emergency Preparedness
9. Home safety

(Sheets and Mahoney-Gleason, 2010)

Veterans with MS



- 46,292 Veterans with MS
 - 83% (38,746) Male
 - 16% (7,546) Female

(MSCOE National MS Repository, 2015)

- Est. 19,000 Veterans (est. 41%) with MS receive care at VA

(MSCOE, 2012)

- Need to identify MS Caregivers – possible research study

Who are MS Caregivers?

From 421 MS Caregiver Respondents:

- 60% Female
- 46 years old
- 72% Married or living with partner
- 38% have Children under age 18
- 67% have College or Graduate degrees
- 70% Household Incomes >\$50,000/year
- Median Income = \$79,000
- 58% Full-Time Job



(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)



Bing Images

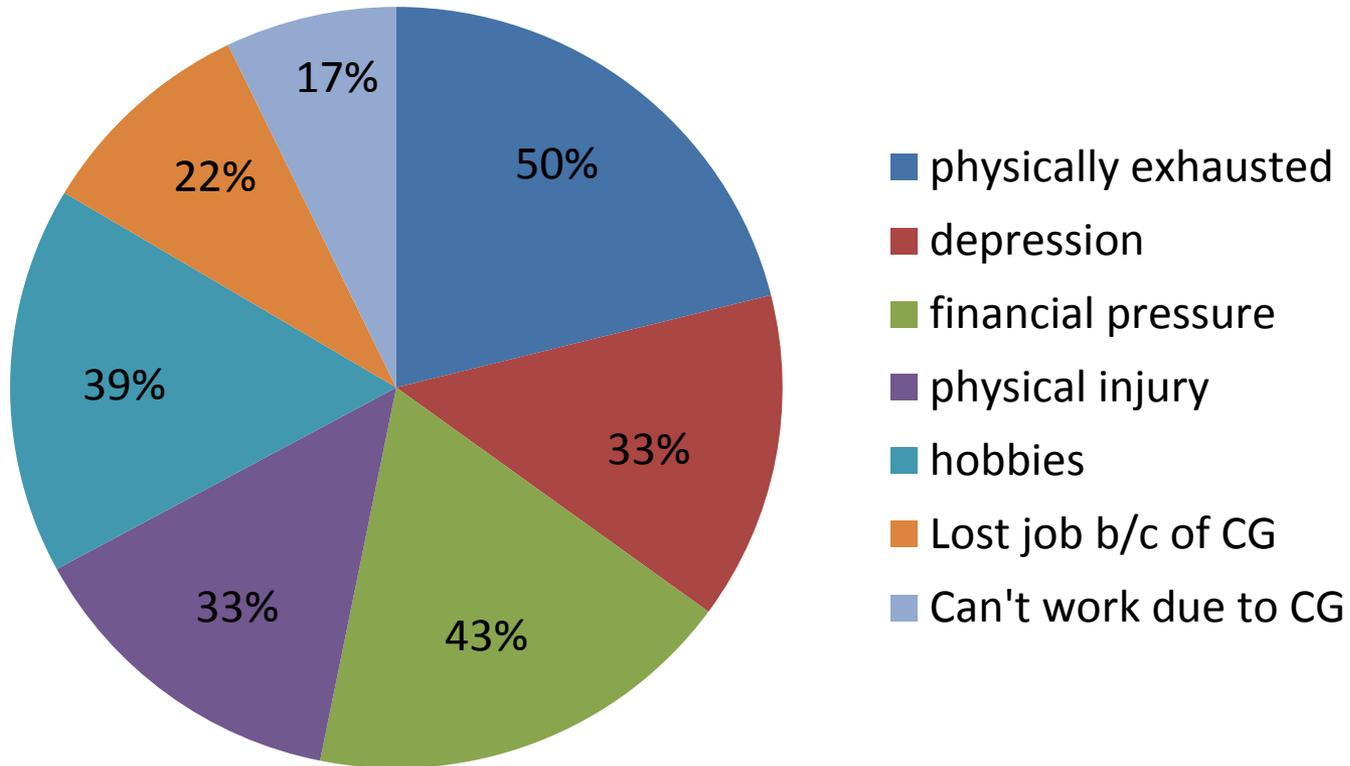
Time Spent Caregiving

- ❖ 24 hours per week
- ❖ 13% spend 40+ hours per week
- ❖ 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)

MS Caregiver Burden



(MS Caregivers Report, 2012)

National VA Caregiver Support Line

www.caregiver.va.gov



- Total Calls = 190,716
 - In 4 months (Feb to June 2015)
- 200 calls per weekday
- 300+ calls some days

(Malcolm, 2015; Wright, Malcolm, Hicken & Rupper, 2015)
- Will be adding our MSCOE Caregiver page to Caregiver Website under Resources

National VA Caregiver Support Line

www.caregiver.va.gov



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)

VA MS Center of Excellence Caregiver Support & Education



- **Monthly Caregiver Call**
 - Social Worker Facilitated
 - Average # Calling In = 15
 - [Click for Flyer](#)
- **MSCOE Caregiver Webpage:** www.va.gov/MS/Veterans/Caregivers
- **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



- Health
- Benefits
- Burials & Memorials
- About VA
- Resources
- Media Room
- Locations
- Contact Us

VA » Health Care » VA Caregiver Support » Caregiver Toolbox » Diagnosis Care Sheets

VA Caregiver Support

- ▼ Caregiver Program
 - VA Caregiver Support Home
 - Caregiver Services
 - Services for Caregivers of Post-9/11 Veterans
 - ▶ What's New
 - ▶ Staying Strong
 - ▼ Caregiver Toolbox
 - Caregiver Toolbox
 - New to Caregiving
 - Diagnosis Care Sheets
 - Everyday Tips and Checklists
 - Staying Organized
 - Help Near Home
 - ▶ Caregiver Connections
 - Additional Resources
 - Caregiver Chronicles
 - ▶ More Health Care

Diagnosis Care Sheets

We know what you are thinking. You don't speak Latin, and you don't have a medical degree. But you still need to understand the medical condition of the Veteran you care for and how to manage it. VA created plain-language care sheets to give you the bottom line on managing the medical condition for the Veteran you love.

We are continuing to add new care sheets to the website on a regular basis. If there is a specific diagnosis care sheet you're looking for and would like to see it added to our list, please e-mail Margaret Kabat at Margaret.Kabat@va.gov to let us know.

[Alzheimer's Disease](#) (PDF)

[Post-Traumatic Stress Disorder \(PTSD\)](#) (PDF)

[Traumatic Brain Injury \(TBI\)](#) (PDF)

[Multiple Sclerosis \(MS\)](#) (PDF)

[Amyotrophic Lateral Sclerosis \(ALS\)](#) (PDF)

QUICK LINKS

Hospital Locator

NEED HELP?

Find your local Caregiver Support Coordinator

How can we help you? I need help with:

Make a selection

Subscribe to Receive Email Updates

CAREGIVER SUPPORT LINE

1-855-260-3274

SERVICES FOR CAREGIVERS OF POST-9/11 VETERANS

Multiple Sclerosis Centers of Excellence

▼ Multiple Sclerosis

Multiple Sclerosis Centers of Excellence Home

▼ Veterans

Benefits

Caregivers

Complementary and Alternative Medicine

Find a Clinic

Frequently Asked Questions

Living with MS

Resources

Support Services

Symptom Management

Veteran Stories

► Professionals

► Products

About MSCOE

Contact MSCOE

► More Health Care

QUICK LINKS

Family Caregivers/Partners - Taking Care of You!



Family caregivers and Care Partners are very important to our Veterans with MS. Taking care of yourself is as important as taking care of your loved one with MS. If you aren't healthy, it's harder to provide good care.

The website link [VA Respite Care](#) gives 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 [VA Caregiver Support Line](#) at (855) 260-3274 or go to [VA Caregiver Support Website](#). A Caregiver coordinator can tell you about benefits for you and your Veteran with MS.

The VA Caregiver Support Website also has a [VA MS Fact Sheet for Family Caregivers](#) and a [VA Caregiver Workbook](#) to help you with caregiver related issues.

Monthly MS Caregiver Calls

[Click for Flyer](#)

**1-800-767-1750
code: 43157#
4th Monday each
month
(No call in May or
Dec)
11am (PST)
12pm (MT)
1pm (CT)
2pm (ET)**

**June 22, 2015
11am PT/2pm ET**

Topic:

[Emergency Preparedness](#)

Maryann Hibbs,
RN, BSN, MSCN
BSBA, MSPL
Pittsburgh VAMC

Multiple Sclerosis Caregivers - News and Articles



Emotional Changes in the Veteran with MS: Tips for the MS Caregiver

By Margaret Kazmierski, 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](#)

Caregiver Wellness by Susan K. Johnson, RN, BSN,
Portland, OR > [Read the article](#)

MSCOE Caregiver Research and Professional Presentations

Interested in what research says about MS Caregivers?
Check out our [MSCOE studies involving VA MS Caregivers!](#)

Check out our [MSCOE Social Worker presentations](#) at
international and national Conferences about MS Caregivers!

past presentations

Facilitators



Maggie Kazmierski
MSW, LCSW-C,
MSCS



Alicia Sloan
MPH, MSW, LICSW



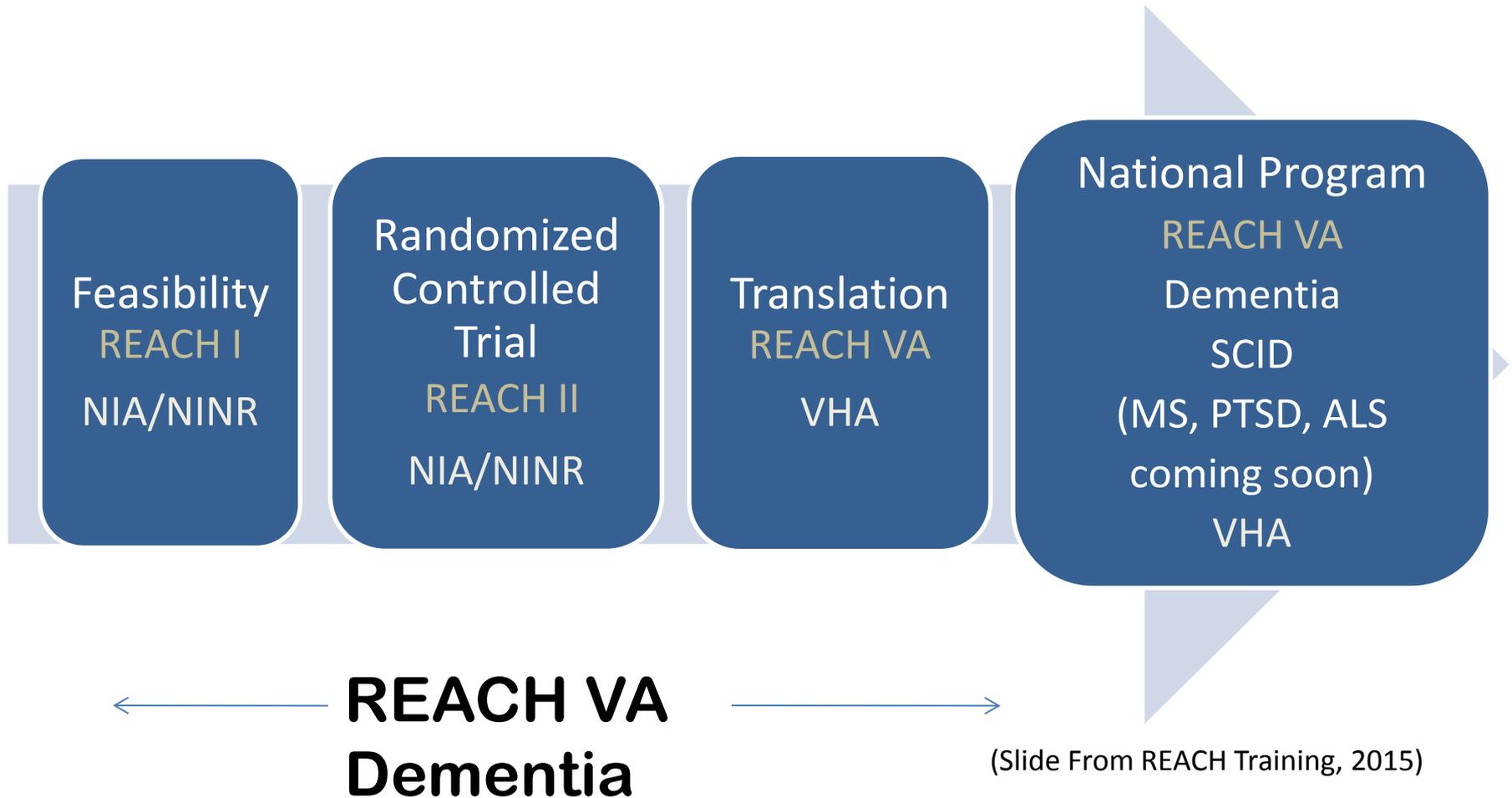
Jan Spencer
MSW, LCSW

MSCOE Caregiver Call Educational Topics

- Emergency Preparedness
- Understanding MS Mood Changes
- Easing Pain in MS for Your Loved Ones and Yourself
- Caregivers: Working Well with Your MS Providers
- Caregiver Communication Strategies
- Occupational Therapy
- Bend and Not Break: Controlling Spasticity Before it Controls your Loved Ones
- Caregiver Stress Management
- Sharing Caregiving Stories
- Caregiver Research
- Caregiver Support Program at the VA
- Travel Resources for Travelers with Disabilities

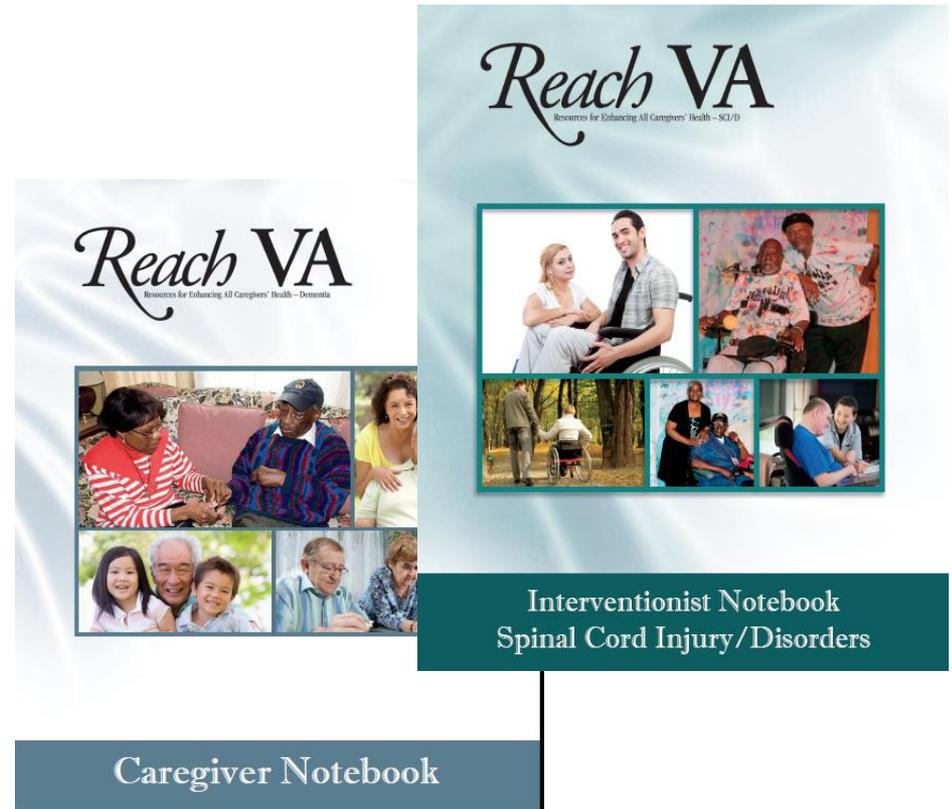


REACH VA Trajectory



REACH VA Materials

- Interventionist Notebook
 - General Training via TMS
 - Easy to “grab and go”
 - Scripts, guidelines, resources, talking points
 - Will be MS-specific next year
- Caregiver Notebook
 - For each caregiver to use & keep forever
 - Educational materials specific to MS issues
 - Stress and coping
 - Communication/Behavioral
 - Health/Wellness
 - Safety



(Slide adapted From REACH Training, 2015)

REACH VA

Evidence-Based Caregivers Improvements In...

- ✓ Burden
- ✓ Depression
- ✓ Anxiety
- ✓ Troubling patient behaviors
- ✓ Caregiver frustrations (abusive behaviors)
- ✓ Stress
- ✓ Safety concerns
- ✓ 1.6 hours/day decrease in time on duty



(Nichols, et al., 2014)

(Slide adapted From REACH Training, 2015)

REACH VA Intervention



- **Active Phase**
 - 4 Individual Core Sessions
 - 2-3 month period
 - Face to face or by telephone or telehealth
 - Optional additional sessions
- **Maintenance Phase**
 - Additional problems/stress issues as needed
- **Optional Telephone Support Groups**

(Slide adapted From REACH Training, 2015)

REACH MS - Risk Priority Inventory (RPI)

- ❖ Risk appraisal of caregiving concerns
- ❖ Addressed in REACH sessions
- ❖ Drives Intervention
- ❖ Caregiver Assessments:
 - Health/Physical Well-being
 - Social and Emotional Support
 - Frustrations and Vigilance
 - Mood (PHQ-4)
 - Well Being (Zarit Burden Inventory, Short Version)
 - Caregiving Tasks in Multiple Sclerosis Scale (CTiMSS) (Pakenham)
- ❖ Care Recipient - Issues or behavioral concerns; safety

MS REACH VA

Example of Chapter Reviews Completed by MSCOE Social Workers

- ✓ Risk Priority Inventory (RPI)
- ✓ Communicating with Health Providers
- ✓ Communicating with Others – Asking for Help
- ✓ Challenging Feelings
- ✓ Depression
- ✓ Emergency Situations
- ✓ Family Roles
- ✓ Navigating the System
- ✓ Communicating with each Other
- ✓ Financial and Legal Issues

Practice Activity

- Groups of 3-5 people
- Introduce yourself: name, provider role, work place, etc.
- Pick a spokesperson to share the group's ideas.
- What modalities would work in your setting?
- Can you develop a telephonic group?
- Would a face to face group work? How about REACH?
- Draft a plan! What would it take to start your own support program?
- What are the barriers?
- Who would support it?
- What does the time line look like for implementation?

Bottom Line: Focus on the Caregiver!



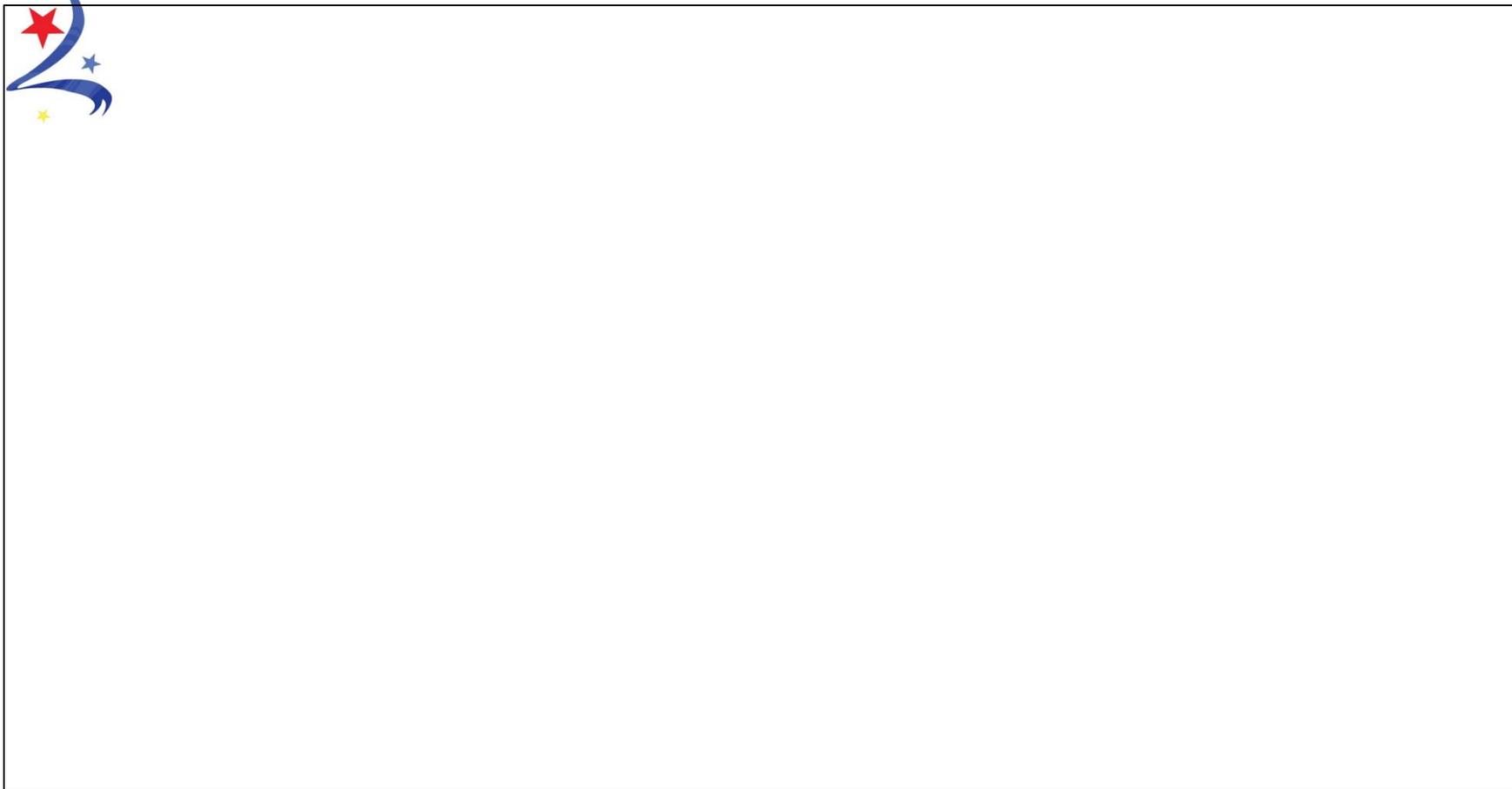


Small Group Ideas

- Group 1
- Group 2
- Group 3
- Group 4



Small Group Ideas



What are YOUR next steps?



- What will you do with this knowledge?
- How will you change your practice?
- What can WE do to help facilitate your plans?
 - **MSCOE SW Education call:** Would you want to join a networking call for MS SW?
 - **MS SW EMAIL Group:** Would this be a good resource for exchanging ideas and resources?

Resources

VA MS Centers of Excellence (MSCoE) Website

- ❖ MSCOE Caregiver page: www.va.gov/MS/veterans/caregivers

VHA Resources

- ❖ VA Caregiver support line: (855) 260-3274
- ❖ VA Caregiver Support: 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/GERIATRICALS/Guide/LongTermCare/Respite_Care.asp
- ❖ VA MyHealthVet - Caregiving Information - www.va.gov/MS/veterans/caregivers/#sthash.B0GpOaKG.dpuf

MS – Specific Resources:

- ❖ 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>

Paralyzed Veterans of America (PVA) Caregiver Support

www.pva.org/site/c.ajlRK9NJLcJ2E/b.6306123/k.B389/Caregivers_Support.htm

Caregiver Assessment Tools

- Zarit Burden Scale (Zarit, 1980)
Printable: www.aafp.org/afp/20001215/2613.html
- Caregiver Strain Index (CSI) (Robinson, 1983)
<http://consultgerirn.org/uploads/File/Caregiver%20Strain%20Index.pdf>
Modified: http://consultgerirn.org/uploads/File/trythis/try_this_14.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

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Note: To connect directly to websites listed, make sure you are in “Slide Show” view and hover mouse over hyperlink and click.

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**I alone cannot change
the world, BUT I can cast a
stone across the waters to create
many ripples.**

— Mother Teresa

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