

Current Topics in MS

MS Caregivers and Coping During COVID Pandemic: Increasing Caregiver Resiliency

Margaret Kazmierski, MSW, LCSW-C

Senior Social Worker, Spinal Cord Injury/MSCoE-East
VA Maryland Health Care System, Baltimore, MD

Alicia Sloan, MPH, MSW, LICSW

Senior Social Worker, Specialty Care Team
VA Puget Sound Health Care System, Seattle/American Lake (Lakewood), WA



**National
Multiple Sclerosis
Society**

VA



**U.S. Department
of Veterans Affairs**

Veterans Health
Administration

*Multiple Sclerosis
Centers of Excellence*

Diversity, Equity and Inclusion Statement

The National Multiple Sclerosis Society (NMSS) is a movement by and for all people affected by MS. Our voices and actions reflect diversity, equity and inclusion.

We welcome and value diverse perspectives.

We actively seek out and embrace differences.

We want everyone to feel respected and be empowered to bring their whole selves to ensure we make the best decisions to achieve our mission.

NMSS Vision & Mission Statements

Our Vision

A World Free of MS

Our Mission

We will cure MS while empowering people affected by MS to live their best lives

VA MS Centers of Excellence

Mission

Improve the quality and consistency of health care services delivered to Veterans with MS across the country.

Expand care coordination between VA medical facilities through the development of a national network of MS providers within the VHA.

Provide resources to VA providers through a collaborative approach to clinical care, education, research, and informatics.

Your feedback is important

Please take the program survey in the TRAIN and/or TMS websites following the program.

Non-VA: www.vha.train.org

VA: www.tms.va.gov



Margaret (Maggie) Kazmierski, LCSW-C is a clinical social worker with over 20 years of experience with chronic illness, rehabilitation, and aging populations. She works with the Veterans Health Administration MS Centers of Excellence East and is the Senior Social Worker/Spinal Cord Injury Program Coordinator at the VA Maryland Health Care System. She is the current Chair of the Greater DC/Maryland Chapter Health Care Advisory Committee with the National MS Society. She is a part-time adjunct professor at the University of Maryland School of Social Work where she teaches graduate social work courses in Aging.



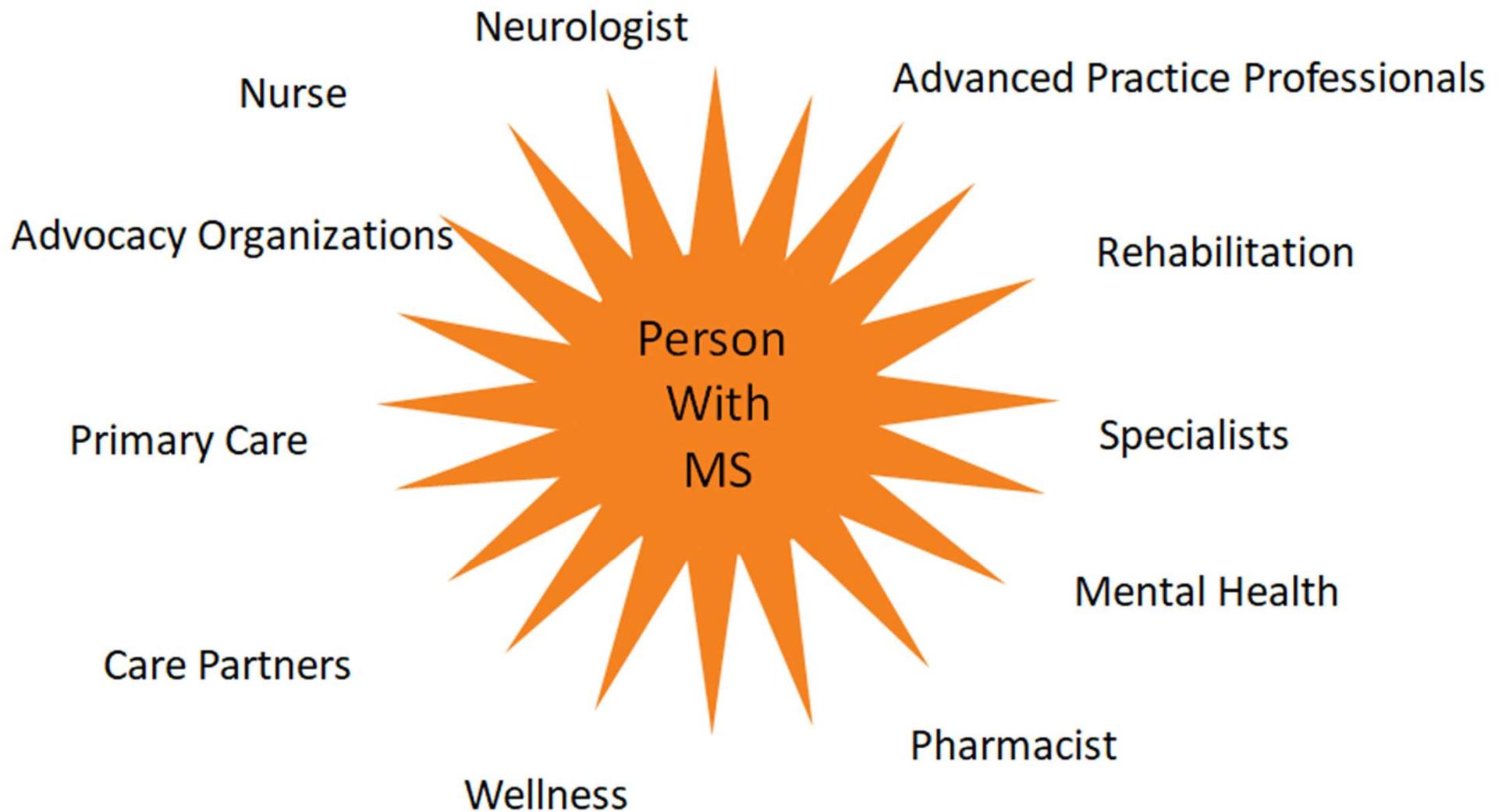
Alicia Sloan, MPH, MSW, LICSW is a clinical social worker with 20 years of experience working with individuals effected by MS and other chronic illnesses. She is an outpatient Senior Social Worker at the Veterans Affairs Puget Sound Health Care System and previously worked as a Research and Special Projects Coordinator for the Veterans Health Administration MS Center of Excellence West. She is on the Greater Northwest National MS Society Healthcare Provider Council and is Secretary of the VA Puget Sound Social Work Service's Diversity, Equity, and Inclusion Committee. She graduated from Tulane University in New Orleans with a Master of Public Health in 1997 and a Master of Social Work in 2001.

Learning Objectives

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

1. Describe 3 ways to increase Caregiver resilience.
2. Describe 2 ways the COVID-19 pandemic has challenged caregiver resiliency
3. Describe at least 2 risk factors of Caregiver Burden and Strain
4. Describe how you can use a video telehealth modality to support and increase caregiver resiliency

MS: A Complex Disease Requires A Comprehensive Approach



Caregivers of MS Veterans

can count on an expert
multidisciplinary VA team
to partner with them



- Lynda Hillman, DNP, ARNP, MSCOE at 2nd Annual Caregiver Summit, VA Puget Sound, June 24, 2021

Who are Caregivers of MS Veterans?

- 96% are female
- 70% are spouses or partners of the MS Veteran
- 80% live in Veteran's household
- 30% spend more than a decade as caregivers

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



Who are Caregivers of People Living with MS?

- 61.9% Male
- 51.1 years old mean age
- 11.9 years mean duration of caregiving
- Caregiver burden (stress)
 - 35.6% mild burden
 - 13.7 % high burden
- 43.4% of MS care partners missed work in the last year due to caregiving
 - Missed a mean of 18.4 days
 - Number of days missed depends on course of MS; PPMS is the highest w/mean of 40.1 days



MS Caregivers Defined

“MS is like an uninvited guest that shows up at your home, makes a mess and doesn’t leave — but that means that the entire family is having to form some kind of a relationship with this uninvited guest.”
(Kalb, 2016)

“Informal caregivers are the primary resource allowing people with MS to remain in their homes.” (Dunn, 2011)

Risk Factors of Caregiver 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
- Mobility of care recipient
- Older age



(Martindale, et al., 2020; 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)

Caregiving in a Pandemic



- Add in a global pandemic...
- Pressure on Caregivers has grown exponentially.
- Everyone In The World changed how we communicate with each other during quarantine in the wake of the virus.
- Everyone, including Caregivers, had to adapt.



VA Communication During a Pandemic



“VA infrastructure was ahead of most other health system in terms of readiness for telehealth and maintaining access to care.”

(Haselkorn, Fed Pract. 2021)

“We had been doing telemedicine for a long time before the pandemic and we were in a better position than a lot of other health systems to shift to a virtual format with COVID-19. We had to ramp up a little bit and get our tools working a little more effectively for all clinics, but I think we were prepared to broadly execute telemedicine clinics for the pandemic.” (Wallin, Fed Pract. 2021)

Impact of the COVID-19 Pandemic on Multiple Sclerosis Care for Veterans, Fed Pract. 2021

<https://connectedcare.va.gov/terms/connected-health/tabs/Solutions-for-Veterans#va-telehealth-services>

Communication During a Pandemic



Patient Tips for a Successful Telehealth Appointment (NMSS)

Insurance Coverage

- Ensure that your insurance currently covers telemedicine and understand your out-of-pocket expense
- Check that your healthcare provider is licensed in the state you plan to receive telemedicine care

Connectivity

- You will need a charged computer, smartphone, or tablet available with attached/integrated camera and stable bandwidth
- Consider having a care partner attend to help maneuver the camera
- Download the required platform prior to appointment, test it out, consent and consult with your practice administrator if any difficulties arise
- Once you are connected for your visit, do not leave that location

<https://www.nmss.org/education/teaching-MS/Comprehensive-Care/Make-the-Most-of-Your-Doctor-Visits/Tips-for-Successful-Telemedicine>

Communication During a Pandemic



Patient Tips for a Successful Telehealth Appointment (NMSS)

Environment

- Treat your visit like you would when receiving in-person care – ensure that your room is private, well lit, free of distractions and clutter, and is quiet
- Examination may include walking – clear space and wear appropriate clothes/shoes

Preparation

- Write down your top one to three concerns
- Have an updated list of allergies, medications, and any needed refills
- It may save time to send any required forms to your healthcare provider beforehand and ensure they have received them

Safety

- Ensure your healthcare provider has your updated address, phone number, and emergency contact at the time of your visit

Caregiver Burden and COVID-19



“...the burden fell hard on the caregivers. But they are quite resilient, and it would take more than a global pandemic to stop them...showing tenacity and integrity in maintaining the Veterans’ health and dignity. They are truly an inspiration.”

- Ida Umentum, Caregiver Support
Coordinator, Milwaukee VA Medical Center, VA
Insider, August 26, 2020.



VA Video Connect (VVC) Clinical Video Telehealth (CVT) : Caregiver Support Group

Example: Caregivers to Veterans who receive care from VA Puget Sound Rehab Care Services, ongoing twice monthly group

- Check-In Positive/Challenges
 - Encourage Group support and connection, reduce isolation
 - Share resources, challenges, solutions
 - Share and process feelings
- Mindfulness Activity
- Education
 - Present and promote self-care skills
 - Develop coping skills
- Rants & Raves





“People who are resilient have the ability to grow from adversity. They can learn things about themselves, about what they value. They learn that they can get through tough things.”

Dawn Ehde, PhD.
University of Washington

Source: [Resilience: Addressing the Challenges of MS](#) National MS Society and MS Society of Canada, North American Education Program, 2016.

Resiliency in Caregiving

Resilience is your ability to withstand, recover, and sometimes grow when faced with adversity; it is an active process of enduring and successfully coping. Resilience is **bouncing back after a crisis**. It's also **bouncing forward** to adjust to a “new normal.”

<http://partnersonthepath.org/family-caregivers/caregiver-resilience/>

Bouncing Forward...

The American Psychological Association ([2014](#)) defines resilience as “the process of adapting well in the face of adversity, trauma, tragedy, threats or even significant sources of stress.

Resilience is the ***process of adapting*** in the face of tragedy, where posttraumatic growth refers to ***positive changes*** experienced as the result of adversity in life or a life-altering crisis.

Post-Traumatic Growth

What is *posttraumatic growth*?

It is positive change experienced as a result of the struggle with a major life crisis or a traumatic event..



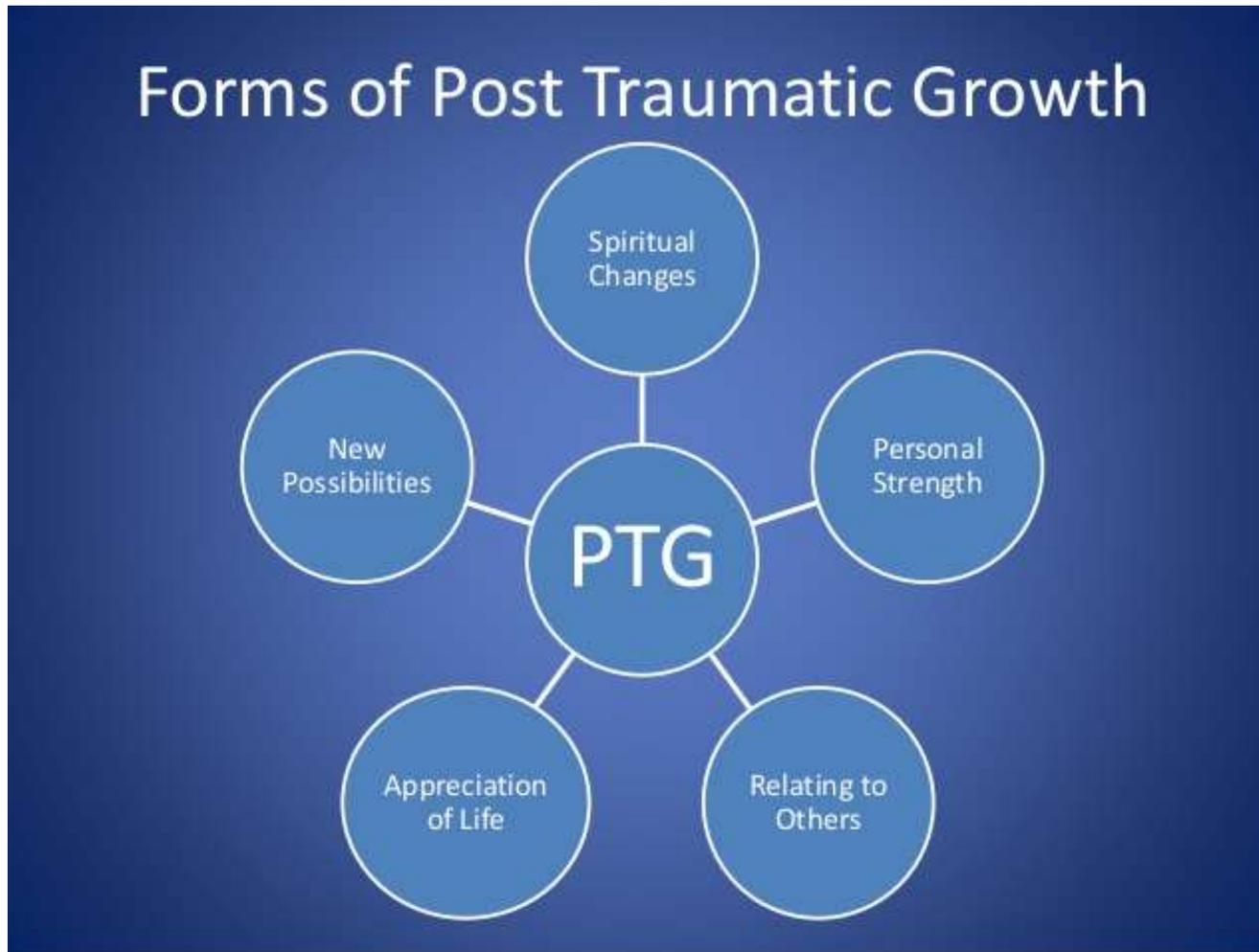
Post-Traumatic Growth



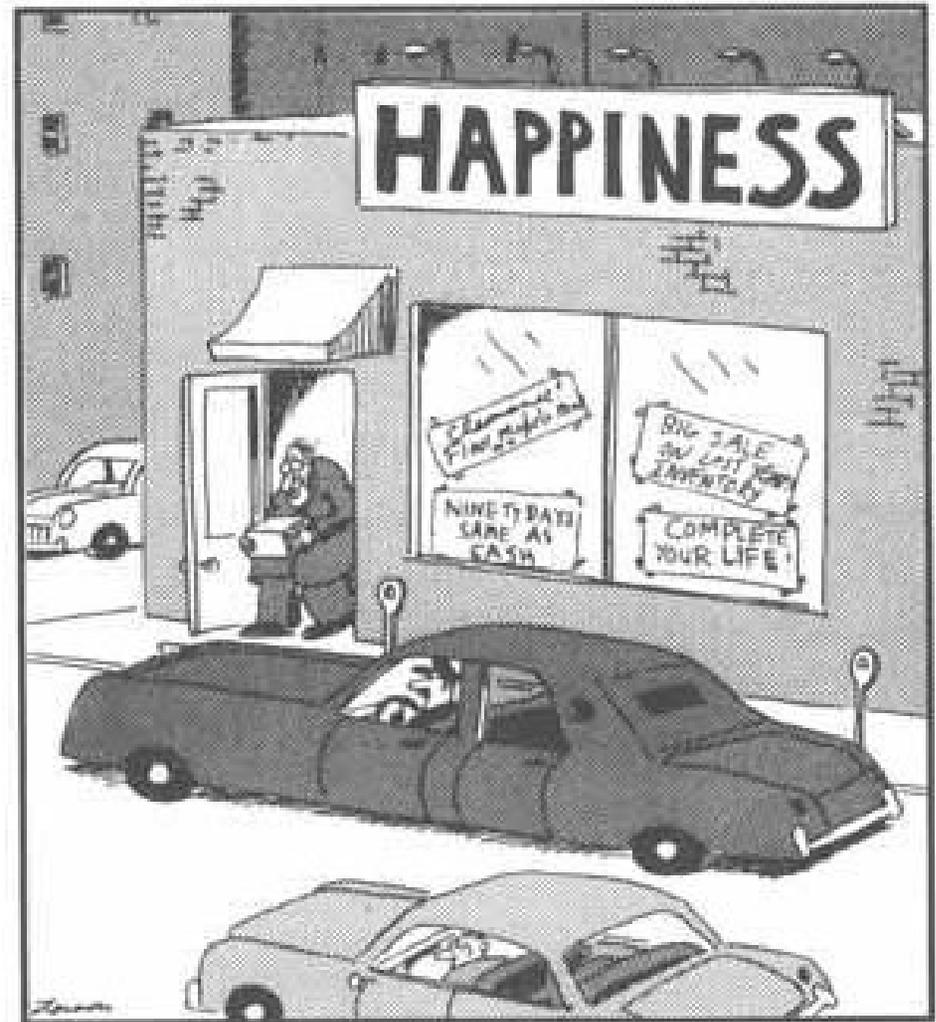
Post-traumatic growth indicators:

- Spirituality
- Social Support
- Acceptance
Coping

Post-Traumatic Growth



Positive Psychology



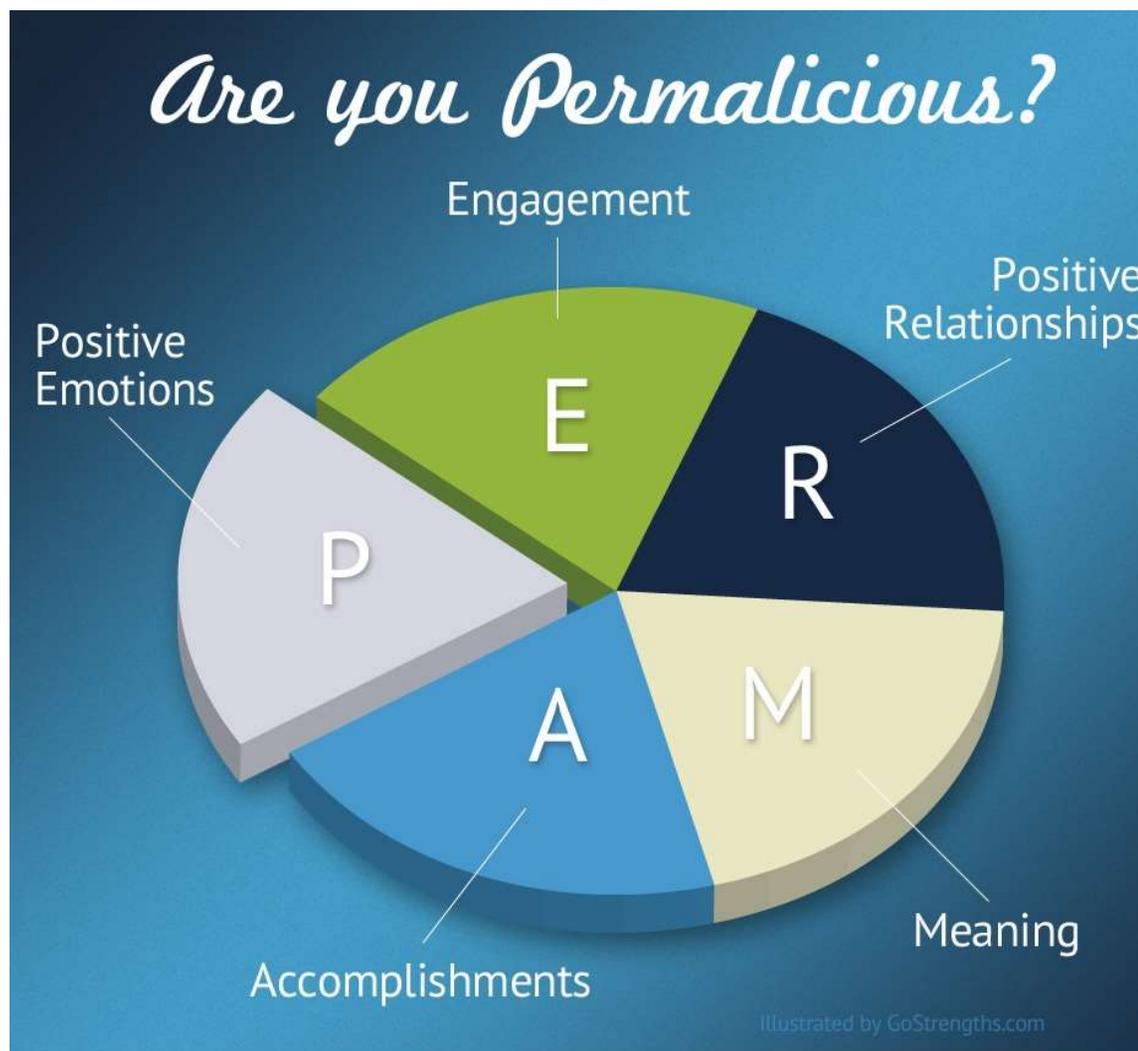
His few friends had told him he could never buy it, but Mr. Crawley surmised that they just didn't know where the store was.

Positive Psychology

Positive Psychology is the scientific study of human flourishing, and an applied approach to optimal functioning. It has also been **defined** as the study of the strengths and virtues that enable individuals, communities and organizations to thrive (Gable & Haidt, 2005, Sheldon & King, 2001).

<http://ppc.sas.upenn.edu/>

Positive Psychology and Resiliency



Concept by Martin Seligman - Source: Seligman, M. E. (2011). *Flourish*. North Sydney, N.S.W.: Random House Australia. Illustrated by GoStrengths.com

Harnessing Resilience

Bridging the concepts of Resilience in the individual with MS to the caregiver/care partner who is also experiencing the stressors of living with unpredictable disease

Source: [Resilience: Addressing the Challenges of MS](#) National MS Society and MS Society of Canada, North American Education Program, 2016.

Harnessing Resilience

Self-inventories, questionnaires and self-assessments—can be used in caregiver support.

Clinical tools aide to narrow what attributes are there to validate and elicit.

[Authentic Happiness, University of Pennsylvania](#)

Harnessing Resilience

Learning the ABCD's

- **A**dversity
- **B**elief
- **C**onsequence
- **D**isputation

How can we apply this to our intervention with caregivers?

Harnessing Resilience

Numerous lifestyle factors contribute to resilience in caregivers too

- Social Connections
- Physical Wellness
- Realistic Goals
- Practicing Gratitude
- Positive Emotions
- Mindfulness/Meditation
- Practicing forgiveness - Let it go!
- Ok to Feel the Negative Emotions

Caregiver Case Study

Caregiver Case Study: Lori, The Daughter

- Lori's dad, 64 year-old, 80% SC, Veteran with PPMS, diplopia, numbness, dementia, cognitive deficits, hip fracture last year, now wheel-chair bound, participates in the Physical Rehabilitation Services MS Clinic at VA Puget Sound
- Needs assistance/supervision for dressing, bathing, toileting
- Independent in eating but dropping utensils more often
- Cannot do food prep or cleanup
- Requires assistance for bathing
- Transfers - Needs standby assist for bed to chair, chair to toilet. Needs assistance for other transfers
- Physically improved with rehab therapies
- Shouldn't drive
- Cognitively impaired
- Dementia
- Can't live on his own
- Lives with Lori, her husband, 2 grade-school aged sons

A MS Caregiver Asks for Help



- Listen to their Caregiver Story
- Review possible caregiver resources
- Refer to resources, other providers
- Explore options for self-care
 - Support Groups
 - Family/friends assisting
 - Respite
- Identify Caregiver's inner resources/strengths.
Acknowledge resilience.

Lori Asks for Help...

“I need a break!”



- **COVID-19 Pandemic...**
- No respite since COVID – 19 pandemic started
- Crying on the phone
- 4 square breathing technique
- Camping Trip Planned for long weekend with family
- Lori is finishing college and graduates soon – will have more time
- Her children are home - online school, husband works outside home



RCS Video Telehealth Caregiver Support Group

Lori's Experience

- **Group Support and Understanding:** Coming to this support group helps me not to feel so alone.”
- **Sharing resources, challenges:** Finding a balance
- **Processing feelings:** I'm overwhelmed. I need a break!
- **Mindfulness Activity to Develop Coping Skills:** 4 square breathing
- **Promoting self-care:** Asking for help of others so I can go camping with my family.
- **Education:** Resilience discussion & drawing resilience
- **Rants & Raves:** Respite is there, but...Pandemic won't let me take it.”



Resources

VA Caregiver Supportive Services



- VA MS Social Worker and MS Team support: individual, support groups, VA REACH program
- Homebased Primary Care (HBPC) if in VA catchment area
 - to reduce travel to VA, at home “house calls” by PCP & Team
- Homemaker/Home Health Aide (H/HHA) and Veteran Directed Care (VDC) programs
- VA Respite - 30 days a year
- Bowel and Bladder Program – family/friend or agency
- VA Caregiver Support Program www.caregiver.va.gov
 - VA Caregiver Support Line: 855-260-3274
- Campaign for Inclusive Care: CIC-Covid19-Tip-Sheet.pdf (hiddenheroes.org)

VA References

1. VHA MS Centers of Excellence: <https://www.va.gov/MS/veterans/caregivers>
2. VA Video Connect flyer: https://mobile.va.gov/sites/default/files/flyer-va-video-connect_0.pdf accessed 7/10/2021.
3. Office of Connected Care, VA Telehealth (2021). VA Video Connect Web 2 May 2021 User Guide.
<https://vaots.blackboard.com/bbcswebdav/library/LibraryContent/VeteranFacing/VA%20Video%20Connect%20Web%202%20User%20Guide%20for%20Veterans.pdf>
4. VA Research on Caregivers:
<https://www.research.va.gov/topics/caregivers.cfm>
Fact Sheet:
https://www.research.va.gov/pubs/docs/va_factsheets/Caregivers.pdf

NMSS MS Caregiver Support



MS Navigator[®]

Resource Assistance Examples

- Financial assistance
- Social and emotional support
- Home & vehicle modifications
- DME & assistive technology
- Respite care & home health

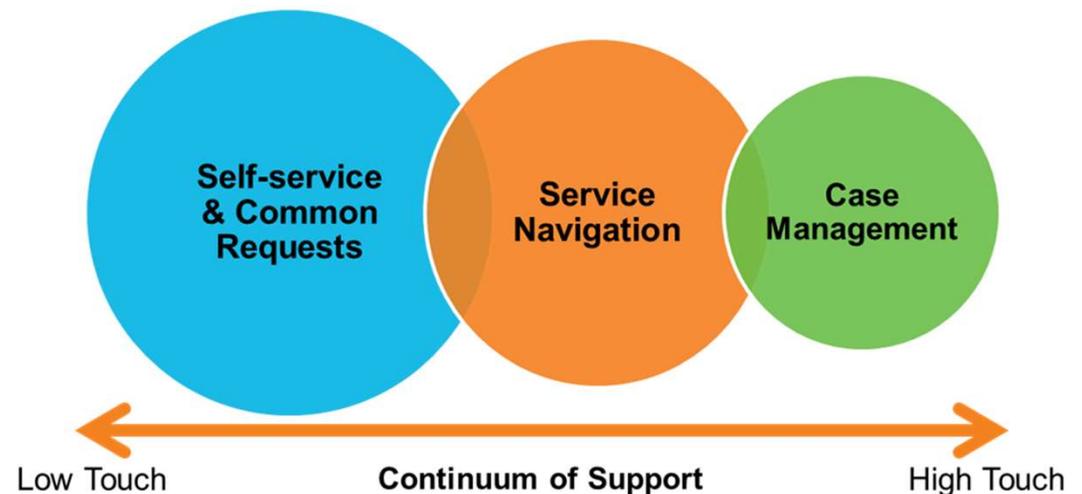
Call, Chat or Email

1-800-344-4867

nationalMSSociety.org

ContactUsNMSS@nmss.org

Monday-Friday, 7am–5pm MT



NMSS MS Caregiver Support



Most MS self-help groups are open to care partners! Search and check each group for specific information

[Join a Local Support Group](#)

Peer Support Virtual Care Partner Online Group – just for care partners!

[MS Care Partner Group : National MS Society](#)

Care Partner Resources and Information

[Family Matters : National MS Society](#)

[Carepartners : National MS Society](#)

[Carepartner Support Resource List : National MS Society](#)

[A Guide for Caregivers](#)

Resilience Resources

National Multiple Sclerosis Society:

<https://www.nationalmssociety.org/Resources-Support/Library-Education-Programs/Resilience-Addressing-The-Challenges-Of-MS/Virtual-Resilience-Toolkit>

- * Supportive Virtual Environment-Can be for the individual with MS or with a care support partner
- * Discussion with each other regarding what works and what does not
- * Less isolative and more connection even virtually

Resilience Resources

CAN DO MS

<https://www.cando-ms.org/multiple-sclerosis-programs/embracing-carers>

References

1. Adelman, R.D., Tmanova, L.L., Delgado, D., Dion, S., Lachs, M.S. (2014) Caregiver Burden: A Clinical Review. *JAMA*. 311(10), 1052-1059. doi:10.1001/jama.2014.304
2. Bambara, J.K., Turner, A.P., Williams, R.M., Haselkorn, J.K. (2014) Social support and depressive symptoms among caregivers of veterans with multiple sclerosis. *Rehabil Psychol*. 59(2):230-5. doi: 10.1037/a0036312. Epub 2014 Apr 14. PMID: 24730574
3. Buhse, M., Ratta, C.D., Galiczewski, J., & Eckardt, P. (2015). Caregivers of Older Persons With Multiple Sclerosis: Determinants of Health-Related Quality of Life. *Journal of Neuroscience Nursing*, 47(2), E2-E12.
4. Chen, H., and Habermann, B. (2013). Ready or Not: Planning for Health Declines in Couples with Advanced Multiple Sclerosis. *J Neurosci Nurs*. 45(1):38–43. doi:10.1097/JNN.0b013e318275b1f9.
5. Ghafari, S., Khoshknab, M.F., Norouzi, K., Mohamadi, E. (2014). Spousal Support as Experienced by People With Multiple Sclerosis: A Qualitative Study. *Journal of Neuroscience Nursing*, 46(5), E15-E24.
6. Khan, F., Pallant, J., Brand, C. (2007). Caregiver strain and factors associated with caregiver self-efficacy and quality of life in a community cohort with multiple sclerosis. *Disability and Rehabilitation*, 29(16), 1241 – 1250.
7. Martindale-Adams, J., Nichols, L., and VA REACH MS (Resources for Enhancing All Caregivers ' Health – MS) Workgroup:...**Kazmierski, M.**, ...**Sloan, A.**, ...**Spencer, J.** (2016). Caregiver Notebook – MS. REACH VA Program. Caregiver Center. Memphis VA Medical Center. U.S. Department of Veterans Affairs.
8. O'Connor, E.J., and McCabe, M.P. (2011). Predictors of quality of life in carers for people with a progressive neurological illness: a longitudinal study. *Qual Life Res*. 20:703–711. DOI 10.1007/s11136-010-9804-4.
9. Schultz, R. and Beach, S.R. (1999). Caregiving as a Risk Factor for Mortality. The Caregiver Health Effects Study. *JAMA*, 282:23.2215- 2219.
10. Wallin, M. Haselkorn, J. Spain, R. Maloni, H. (2021) Impact of the COVID-19 Pandemic on Multiple Sclerosis Care for Veterans, *Fed Pract*. May;38(4):[Epub ahead of print]

Thank you!

Alicia.Sloan@va.gov

Margaret.Kazmierski@va.gov

Your feedback is important

Please take the program survey in the TRAIN and/or TMS websites. This will give you access to your CME/CE certificate.

Non-VA: www.vha.train.org

VA: www.tms.va.gov

What's On Your Mind?

Please type your question into the **Q&A** area in the lower right corner of your screen.



Thank you and please join us
for the next webinar on
March 28, 2022!

www.nationalMSSociety.org/currenttopics

www.va.gov/MS/products/CME_CEU_calls



National
Multiple Sclerosis
Society

VA



**U.S. Department
of Veterans Affairs**

Veterans Health
Administration

*Multiple Sclerosis
Centers of Excellence*