MSAA
Multiple Sclerosis Association of America
Improving Lives Today!®

presents

The Partnership Of Care: Redefining Caregiver To Care Partner

Live Webinar

Monday, March 18, 2019

8 pm Eastern

Acknowledgement, MSAA and Webinar Participation

MSAA would like to take this opportunity to thank EMD Serono for its support of our MS Awareness Month activities **Spotlighting Care Partner Needs** as part of our overall theme on MS and the Family. Tonight's webinar along with an upcoming live Ask Me Anything program, an audio podcast, and educational programs are made possible through funding support from EMD Serono

MSAA's mission is to Improve Lives Today for people living with MS and their families. Just some of our free services include a national Helpline, equipment and cooling products, MRI funding assistance, educational programs, publications and webinars, mobile phone app, online peer support, and many more. To learn more, please call (800) 532-7667, or visit mymsaa.org

Tonight's webinar will be archived on mymsaa.org, along with other activities as part of the MS and the Family campaign. While watching tonight's webinar, we encourage you to type in your questions about the program in the chat box on your screen. We'll have a Q & A session at the end. You can also use the chat box to ask for technical assistance and a moderator will reply

Guest Presenter:

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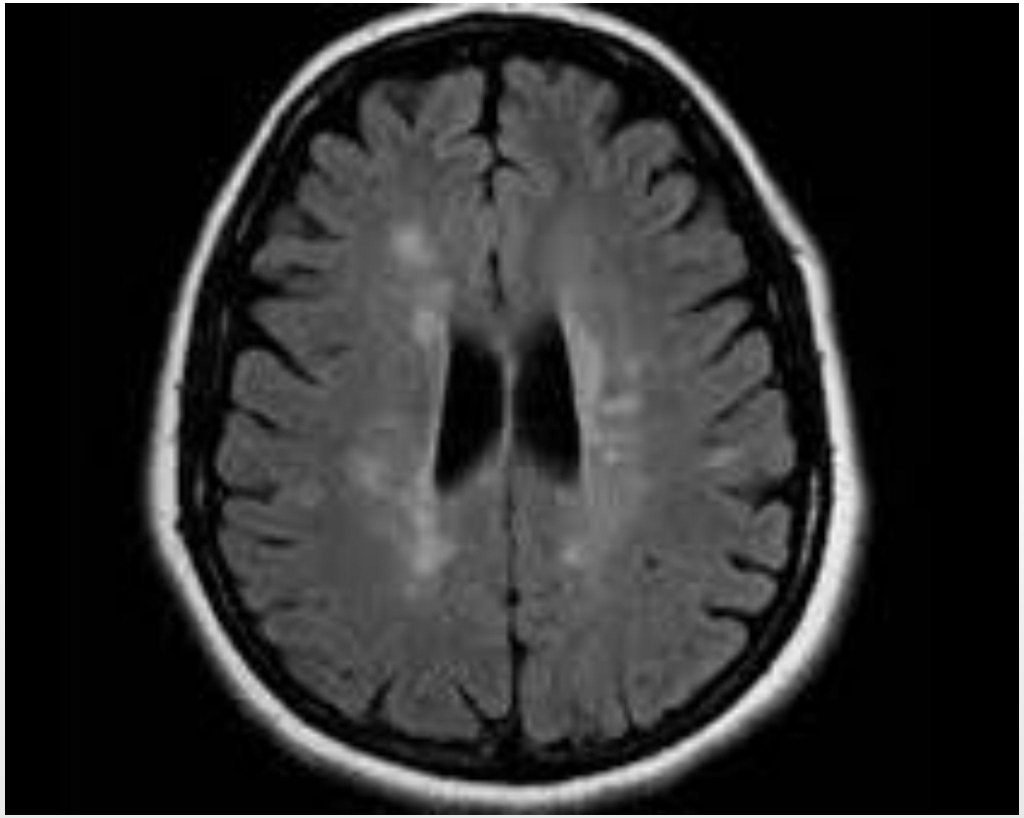
OBJECTIVES

- Define the concept of a care partnership between a person living with MS and the support team
- List roles and responsibilities of the person living with MS and the care partner
- Discuss the importance of self-care for the care partner
- Discuss the importance of communication
- Provide useful resources and tools

STAGGERING STATISTICS

- Approximately one million people in the US have Multiple Sclerosis (MS)
  - Average size of a household is over 2.5 people…so MS affects way more than that
- It affects 3-4 women for every one man
- Most people with MS have the relapsing type
- Fatigue, emotional, and cognitive issues are often the reasons that people of working age with MS leave the work force (rather than physical ones)



https://www.healthline.com/health/multiple-sclerosis/images-brain-mri#1

MS IS UNPREDICTABLE

- Your MS does not look like your friend's or your sister's, and it may never
- That does not take away the anxiety
- Even years of stability do not take away the nagging worry of unknown for many people

IT TAKES A VILLAGE

- Person living with MS
- Friends, family, neighbors
  - In person
  - Virtual community
- Health care providers
  - Physicians, NPs, PAs, nurses
  - PT, OT, ST
  - Psychologist, counselor
  - Exercise specialist, nutritionist
- Hired Help, Community Resources
  - Housekeeper
  - Home health aid
  - Transportation, respite

https://blog.mymsaa.org/it-takes-a-village-to-navigate-this-life-with-multiple-sclerosis/

MANAGEMENT IS COMPLEX FOR MANY

- Disease Modifying Therapy
  - For relapsing forms to decrease relapse rate, slow down disability progression, decrease rate of MRI change
  - For the primary progressive form to slow down disability progression
  - But how do I know when I am "secondary progressive?"
  - When (if ever) can I stop?

- Symptom Management
  - Pharmacologic
  - Rehabilitative
  - Integrative
- Relapse Management
  - Plan
  - Toolbox

WORRIES ARE DIFFERENT…SOMETIMES

PERSON WITH MS

- What if I become disabled and can’t work?
- If my MRI changes, what does that mean?
- Will I run out of treatment options?

CARE PARTNER

- How will I support our family if he/she cannot work?
- What if he/she comes home from the MS doctor upset?
- How do I know his/her medicine is really helping?

http://hrsusa.net/dressing-assistance/

CAREGIVER

Someone who provides hands on assistance with activities of daily living like dressing, bathing, toileting, transferring, feeding

CARE PARTNERSHIP

Suggests that a person living with MS and his or her support partner communicate well in order to:

-manage MS challenges together

-support and care for each other

-allow each other to thrive

https://www.nationalmssociety.org/Living-Well-With-MS/Relationships/Family-Matters/Carepartners

WHO IS ON THE OTHER SIDE OF THE PARTNERSHIP?

- Spouses, parents, siblings in that order
- 1 in 4 millennials are caregivers
- Families are providing 80% of long-term care in general
- Because of demographics of MS
  - More likely to be husbands (~62%), have young families, and to be early in careers

- In MS….
- Top 3 emotions experienced are compassion, fear, and anxiety
- Top 3 negative impacts are on finances, hobbies, and mental health
- Top 3 positive impacts are on relationship with care recipient, children, and other family members

CARE PARTNERS IN MS

- Women
  - Report increased levels of burden or stress
  - Report increased med use for stress, anxiety and sleep
  - Report more health concerns
- Men
  - Report more physical concerns
  - Are less likely to tell their PCP about their role
  - Actually have greater health risks than women
- Children
  - Not equipped to handle primary care partner role, even older teens and young adults

- Spend about 24 hours per week in role
- Have an average age of 52 years
- Miss about 18 days of work per year (>40% miss work in a given year)
- Will change jobs at a rate of about 10% because of role
- Perceive more burden with primary and secondary progressive courses of MS

https://www.topmobility.com/universal-scooter-lift-fully-automatic-p2822.htm?UA-8348507-3&gclid=Cj0KCQiAtvPjBRDPARIsAJfZz0rh0aHJjT6kWjuzqiyPuniK2ww9Q7E9KVU4RIAU6EaT2Jyt2aVVG0MaAhMCEALw_wcB

MOST STRESSFUL SYMPTOMS REQUIRING CARE

- Fatigue
- Mobility
- Bladder issues
- Depression
- Cognitive changes

Whether or not the person
needing care had a choice,
the majority of people caring
for a loved one with MS
would say the role made
them closer to their loved one.

RESPONSIBILITIES OF A CARE PARTNER

- Are best developed TOGETHER
- Depend on the condition of the person living with MS
- May vary day to day
- Change with time, so should be revisited on a regular basis

Emotional	Cleaning	Cooking	Laundry
Errands	Managing household finances	Organizing the family	Bathing/ Toileting
Appointments	Transportation	Health and wellness assessment	Scheduling appointments
Transferring	Catheter Care	Wound Care	Exercising

CARE PARTNER HEALTH

- Reportedly poorer
- Take more meds
- Have twice the rate of depression than general population
- Men have increased risk for stroke and heart disease, more hospitalizations
- Chronic stress of caregiving increases risk for cardiovascular disease, diabetes and cancer

http://hardcorezen.blogspot.com/2011/08/secure-your-own-mask-before-helping.html

WHICH BRINGS US TO SELF-CARE

https://www.health.harvard.edu/blog/dont-take-fatigue-lying-2017041411485

CAREGIVERS REPORT:

- Sleep deprivation
- Poor eating habits
- Failure to exercise
- Not staying in bed when sick
- Postponing or not making needed appointments for themselves

HOW BURNOUT HAPPENS

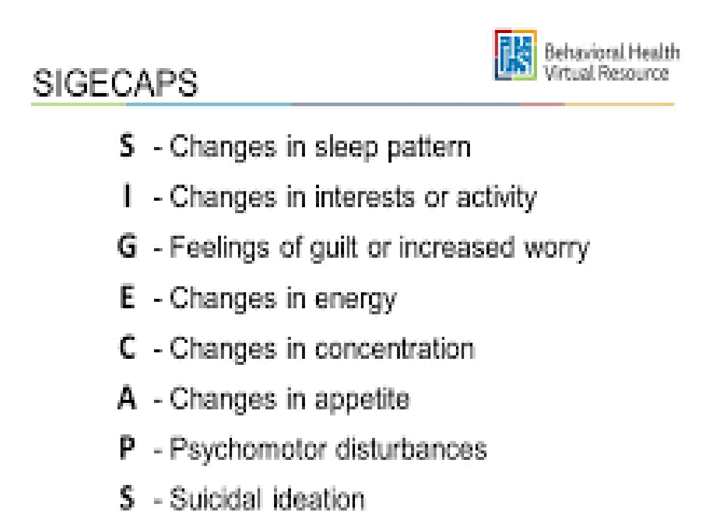
- Major role changes in the relationship and no one is talking
- Sacrificing ones physical and emotional needs can lead you to feel guilty if you feel angry or isolated, and then guilty if you choose to do something for yourself
- Invisible symptoms of MS (cognitive, fatigue, emotional) can be more challenging than physical ones for care partners
    - Others can't see them, so maybe you feel unvalidated or trapped

WARNING SIGNS

BURNOUT

- Are you getting sick frequently?
- Are you always exhausted?
- Do you have mood swings?
- Are you noticing behavior changes or brain fog?
- Are you building anger or frustration?

DEPRESSION



Behavioral Health
Virtual Resource

SIGECAPS

S - Changes in sleep pattern
I - Changes in interests or activity
G - Feelings of guilt or increased worry
E - Changes in energy
C - Changes in concentration
A - Changes in appetite
P - Psychomotor disturbances
S - Suicidal ideation

WHAT DO YOU DO?

- Don’t withdraw
- Ask for help
- Be clear about your needs
- Have a backup plan for care
- COMMUNICATE

SELF-CARE FOR THE CARE PARTNER

- Take regular time outs, don't get sent there!
- Connect with other care partners
- Make time for exercise, recreational activities, fresh air
- Eat healthfully
- Develop a plan for stress management
- Keep routine medical appointments
- Learn proper body mechanics
- Practice positive self-talk
- Identify what you can and can't change

"I'm constantly concerned…that it could be worse…and there is nothing I can do about it."

"If MS gets worse, are we in a place financially that would would be able to live a 'normal' life?"

"Will she be okay if something happens to me?"

"I don't want her to see that I get worried sometimes…I try to be a positive influence….I try not to get frustrated…"

"What's going to happen is going to happen and no amount of worrying is going to change it….I think sometimes I am painfully optimistic."

COMMUNICATION IS KEY

Care Partnership is a Two-Way Street

EFFECTIVE COMMUNICATION

- Should be frequent because of unpredictability of MS
- Speak
  - In specifics
  - In “I” statements and without blame
  - Without sarcastic words or body language
- Listen
  - To confirm
  - Without interruption
  - Without judgement

Warning! Problems previously present
In the relationship will get magnified
In this new relationship!
Address them with a mental health
Professional ASAP!

COMMUNICATION RESOURCES

- Planning Together
  - Be clear about needs
  - Discuss advanced directives and will regularly
  - Make a list of alternative helpers
  - Get FMLA papers filled out BEFORE you need them
  - Make time outs for health and respite…for both of you
  - List problems and solutions in detail
- Consider Counseling
  - Couples counselor, sex therapist
  - Individual

RESOURCES FOR CARE PARTNERS

- MS Association of America
- MS Foundation
- Can Do MS
- National MS Society
  - MS Navigators
- Veterans' Administration
- Family Caregivers Alliance
- Caregiver Action Network
- Eldercare
- National Alliance for Caregiving

In Conclusion…
Words Care Partners Use to Describe the Path:

Satisfying
Honor
Privilege

https://scrubsmag.com/the-pros-and-cons-of-providing-in-home-nursing-care/

…grant me the Serenity
To accept the things I cannot change,
Courage to change the things I can and
Wisdom to know the difference.

References

Can Do MS
Family Caregivers Alliance
MS Association of America
National MS Society: *Guide for Support Partners*
National Alliance for Caregiving: *Multiple Sclerosis Caregivers*

McKenzie, T., Quig, M., Tyry, T., et al. (2015). Care partners and multiple sclerosis: differential effect on men and women. *International Journal of MS Care, 17*(6), 253-260.

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Question and Answer Session

THANK YOU!

This concludes our webinar, **The Partnership Of Care: Redefining Caregiver To Care Partner.**

MSAA would like to once again thank Megan Weigel for her excellent presentation on this very important topic as well as EMD Serono for its funding support of tonight's webinar and additional programs that spotlight care partner needs.

Tonight's webinar and these additional resources will soon be posted to MSAA's website at mymsaa.org.

Please consider completing the very brief evaluation survey that will immediately follow this last slide. On behalf of MSAA, thank you so much for watching!