

#BRAINMATTERS WEBINAR ON DEMENTIA CAREGIVING & CAREGIVERS TAKEAWAY MESSAGES



DR. HALIMA AMJAD, JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICINE

- 1) Educate and prepare yourself. Take advantage of online and in-person information and trainings, healthcare professionals, and others who have walked the same road to get a better sense of what to expect as dementia progresses and what challenges might come up.
- 2) It takes a village and you need support to run the marathon that is dementia caregiving. Everyone's circumstances and what support they can access is different. For my family, our village included immediate and extended family, paid caregivers, my dad's and my mom's doctors, and online Facebook support groups. Every type of support, including emotional and moral support, helped my mom in her caregiving role. Bring in the support that you can.
- 3) Everyone's life story, including the part of the story about dementia and caregiving, is unique. You may not go through what others' have gone through, and you may face issues that others didn't. With dementia, there is a lot that we can't control, but there are also parts of the story that we do write. There are moments of joy, love, and connection that we can find if we look for those moments. When possible, focus on the positives and make memories.

RITA B. CHOULA, MA, AARP

- 1) You are not alone. There are many people dealing with similar challenges you face as a caregiver of someone with dementia. Talking about it and finding support in others can be invaluable to you.
- 2) Asking for help is not a sign of weakness. There is strength in acknowledging that you don't have the answer for everything and need support. Without asking it is hard for people to know your needs.
- 3) The power of observation should not be underestimated. As the family caregiver, learning to take note of and share your observations with providers, other family members, etc. is an important tool to getting the help you and the person you are caring may need.

DR. CHANEE FABIUS, JOHNS HOPKINS UNIVERSITY BLOOMBERG SCHOOL OF PUBLIC HEALTH

- 1) There are community resources available to caregivers that people are often unaware of but that can provide services such as training or respite care (via Area Agencies on Aging, etc.).
- 2) Available resources may provide assistance to both caregivers and care recipients.
- 3) I encourage caregivers to have conversations with older family members early to understand the type of care they prefer to receive in the event that they require assistance with decision making (e.g., living at home with help, moving to assisted living).

ILENE ROSENTHAL, ALZHEIMER'S ASSOCIATION (GREATER MARYLAND CHAPTER)

- 1) First, learn everything you can about the diagnosis, how it progresses, what challenges you may encounter, and how to deal with them. Sign up for caregiver education. And make a note of the Alzheimer's Association Helpline phone number at 800-272-3900. Experts are available 24/7 to answer any question, conduct a care consultation, provide guidance to get you through a stressful situation, and provide resource lists and tip sheets on a variety of topics.

- 2) Consider legal and financial matters. Start discussions early with your loved one so they can be involved in the decision-making process.
- 3) Ask for help when you need it. This could mean asking family members and friends to help you or reaching out to local service agencies for additional care needs. Build in breaks for yourself. Learn how to relax and pursue some hobbies. Consider joining a support group.

DR. QUINCY SAMUS, JOHNS HOPKINS MEDICINE PSYCHIATRY AND BEHAVIORAL SERVICES

- 1) Despite the significant advancements and new and growing services for caregiver support in Maryland over the past decade, Maryland based data from several federally funded studies show there is still work to do regarding helping caregivers receive help and support for understanding the disease and what to expect, how to find services and supports, and how to make sure they are receiving the support they need for their own emotional health and wellbeing—this is especially true for caregivers of color and living in lower resourced communities.
- 2) Maryland has a new state plan with a number of actions and recommendations included to enhance caregiver supports in various ways and has already received an initial kickstart through legislation of a director level position in the Maryland Department of Health and through some budgetary support for the current fiscal year.
- 3) Studies show that family caregivers during COVID-19 were hit particularly hard. Emerging studies from the pandemic suggest family caregivers had higher than normal stress and greater levels of caregiving intensity for longer periods without respite. The importance of social connectivity and social isolation and loneliness for caregivers and their loved ones with dementia for health and wellbeing was highlighted by the pandemic and the good news is that social connectivity and meaningful activity engagement are now being tested in activity-based interventions like MEMORI Corps to see if these can be addressed. Positive aspects of the pandemic included: a greater appreciation of the influence of social relationships in health and cognitive health; innovations in virtual connectivity and health care; individual growth, coping; and a better sense of how we might work to prevent or mitigate effects from events like this in the future.
MEMORI Corps link: <https://www.hopkinsmedicine.org/psychiatry/research/memori-corps/>

#BRAINMATTERS is a regional collaboration based in Maryland and dedicated to sharing science-based information about brain health, health disparities, memory loss & Alzheimer's disease and related dementias. Links to our partner organizations:

- [Alzheimer's Association, Greater Maryland Chapter](#)
- [Delta Sigma Theta, Inc., Alumnae Chapters \(Annapolis & Columbia\)](#)
- [Global Council on Brain Health](#)
- [Johns Hopkins Alzheimer's Disease Research Center](#)
- [Johns Hopkins Alzheimer's Disease Resource Center on Minority Aging Research](#)

Thank you for joining our webinar on Dementia Caregiving and Caregivers!