



ECHO IDAHO: **Alzheimer's Disease and Related Dementias**

Caring for the Family Caregivers of People Living with Dementia

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Oni Kinberg, MSSW, LCSW

Social Services Director at Idaho State Veterans Home-Boise

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Introduction and welcome



Hierarchy of Needs



What does the group think are the most significant stressors for caregivers

- **Type into the chat what you think the most significant stressors are for caregivers of people with dementia**

Learning Objectives

How do we focus our efforts?

- A majority of caregivers (70%) report that coordination of care is stressful (Alzheimer's Association, 2024).
 - More than half of the caregivers surveyed (53%) said that navigating health care was difficult.
 - 2 in 3 caregivers (66%) also have difficulty finding resources and support for their needs.
- Let's look at the top five stressors for caregivers:
 1. Cost (reported by 42% of caregivers).
 2. Coordinating with multiple doctors (36%).
 3. Securing appointments (35%).
 4. Getting help taking a break (35%).
 5. Finding appropriate doctors (32%).

Research has focused on interventions

- Much past research has looked at the efficacy of interventions in reducing caregiver stress but has not found a strong connection between the intervention and reduced caregiver stress or better health outcomes(Hughes, 2017).
- Assessment, education and skills training, care coordination, counseling and support groups, and respite are the main areas of intervention that have been shown to have an overall positive impact on caregivers.
- More research needs to be done on how to improve health outcomes and reduce stress for caregivers to better target interventions.

Interviews with Caregivers at Support Group

- “What is something that a professional could have done or said that may have reduced your stress when you were caring for your loved one at home.”
- “Would have liked to know more about respite, particularly overnight. If I could have caught up on sleep, I would have been less stressed. I could not figure out how to actually obtain respite care.”
- “I was functioning day to day, and it is hard to ask. In the beginning you are just figuring things out and think you can do more than you can. It was really helpful when I had someone who would call me to check in instead of needing to call and ask for help.”
- “Others don’t get it until they see it. I needed to have family and friends visit to see how hard things were before they would ask if they could help.”
- “It was very frustrating having to tell my story over and over. I think the professionals should take better notes and read the notes before meeting with the caregiver.”
- “Home health was very helpful and validating. It was good to know that I am not crazy and other people were seeing the same things I was. I was very isolated.”

What can we do to help reduce stressors COST!

1. What can health professional do to help with addressing cost of care
2. First thing is to acknowledge that this is a reality and to try and validate peoples concerns versus sweeping this concern under the rug.
3. More than 11 million Americans provide unpaid care for a family member or friend with dementia, a contribution to the nation valued at nearly \$350 billion.
4. Paying caregivers is often not an option for a majority people
5. Lower cost ideas often require creativity
6. Technology (Alexa, cameras, etc.), community (friends, family, church, neighbors), and most importantly recognizing and supporting those providing the care

What can we do to help reduce stressors Coordinating with Multiple Doctors

- Facilitate regular communication meetings or teleconferences among caregivers and all healthcare providers involved in the person with dementia's care plan.
- Utilize technology such as health management apps or online portals to organize medication schedules, appointments, and symptom tracking.
- Provide comprehensive caregiver education programs focused on dementia care to enhance caregivers' knowledge and communication skills with healthcare professionals.

Securing appointments

- Have you experienced individuals who have been frustrated with securing appointments
- What are some strategies we can think of to address this?

Skills to help caregivers secure appointments

- **Early Planning:** Schedule appointments well in advance to secure preferred times and dates, allowing flexibility for unexpected changes.
- **Clear Communication:** Clearly communicate any specific needs or concerns when scheduling appointments with healthcare providers.
- **Follow-Up:** Keep a log of previous appointments and follow-up tasks to ensure continuity of care and timely interventions.
- **Advocacy Skills:** Develop assertiveness skills to advocate for the needs of the individual with dementia, including asking questions and seeking clarifications during appointments.
- **Documentation:** Maintain a record of symptoms, medication changes, and questions to discuss during appointments, facilitating more productive discussions with healthcare providers.
- These strategies can help caregivers navigate the appointment scheduling process more effectively, thereby reducing frustration and improving the overall management of dementia care.

Getting help and taking a break

- **Respite Care Services:** Utilize respite care services, which provide temporary caregiving relief by trained professionals or volunteers. Research indicates that respite care can significantly reduce caregiver burden and stress, allowing caregivers to recharge and attend to their own needs (National Institute on Aging, 2020).
- **Support Groups and Networks:** Engage in support groups or networks specifically tailored for caregivers of individuals with dementia. These groups offer emotional support, practical advice, and opportunities to share experiences with others facing similar challenges. Studies show that participation in support groups can enhance caregiver coping mechanisms and reduce feelings of isolation (Brodaty et al., 2014).

Finding appropriate doctors

- **Local Healthcare Networks:** Connect with local healthcare networks or community health centers that specialize in geriatric care. These centers often have resources and referrals for dementia specialists.
- **Telehealth Services:** Utilize telehealth services to consult with specialists remotely, overcoming geographical barriers and accessing expertise not locally available.
- **Geriatric Care Coordination Programs:** Enroll in geriatric care coordination programs that can help navigate the healthcare system, provide referrals, and coordinate care across different providers.
- **Community Support Groups:** Join local support groups for caregivers of individuals with dementia, where members often share recommendations and experiences about doctors and healthcare providers in the area.

Key Points

- Reduce stigma and encourage engagement
- Be concerned for the caregiver even if they tell you everything is fine
- If possible, have people who can call and reach out instead of waiting to hear there is a problem
- Be creative and try to meet people where they are at (movies, books, support groups, veterans' resources, church resources, insurance resources, online trainings).

References

Here are the references in correct APA format:

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