

Assistance for Caregivers of Persons with Alzheimer's Disease and Related Disorders

What are some of the unique assistance services often unknown in the community?

Overall, caregivers and their friends/family are becoming much more aware that services are available. But they often don't understand what those services can provide, how to buy them or receive them, or how to effectively ask for help from friends and family and/or coordinate purchased or public supports.

Veteran's Services: The majority of caregivers we talk to don't know that their parent who served in the military may be eligible for Aide and Attendance or some other veteran benefit that may help them now in their older years.

Hospice: Hospice palliative and regular hospice is underutilized by caregivers of people with Alzheimer's. Hospice can help with ideas for problem behaviors and medication management.

Powerful Tools for Caregivers: This is a six-week class for caregivers of anyone with special care needs. People must be trained leaders to provide the class. They are typically offered at no cost to participants or for a \$30 book fee. The Area Agencies on Aging, county aging service providers, county cooperative extension agents, and Community Care Networks often have trained class leaders.

Faith Communities: There are several churches and small ministerial councils who are focusing on the needs of caregivers in their congregations. Some are starting caregiver day out programs, some are requesting volunteers help during services so that the caregiver, and often the care recipient, can continue to remain active in church. The NC Baptist Aging Ministry has a formalized volunteer training program, a friendly visitor service and a hotline to assist older adults. The local AAAs, service providers, and businesses often partner to help as well.

Senior Centers: While they may not be an option for later stage socialization, senior centers help find Medicare Part D savings, home safety evaluations or home improvement programs, have free equipment that has been donated, and offer a congregate or home delivered meal connection. They are sometimes staffed with a community resource coordinator as well that has appointment times.

Certified Options Counselors: This is a service becoming more available in the aging and disability community. They are available to meet with caregivers and those who need assistance to help them make a plan for their future needs. Unlike a geriatric care manager or a Project C.A.R.E. family consultant, they do not provide ongoing assistance but can meet with clients in person or by phone.

PACE – Programs of All-inclusive Care for the Elderly: Provides comprehensive health care and services that allow individuals 55 years and older who qualify for nursing facility level of care to remain in the community.

Music Therapy, Use of Service Animals

What is the value of support groups?

Research tells us that education and support, when coupled with any service like respite, makes that service much more beneficial. Below are comments from area family caregiver specialists and Project C.A.R.E. family consultants about support groups. There are a variety of groups for caregivers and people with the diagnosis across the state.

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"This is the one thing I have the hardest time conveying to people. The ones who attend will attest to the importance of talking with people in their same situation."

"Support groups provide immediate, practical help. Members have authentic and common life experiences and work at an intuitive and common sense level. The sense of control improves morale."

"Support groups are vital to families dealing with dementia."

"I have low attendance at support groups, but those that attend say it has saved their life to meet others and be able to come and share."

"Support groups save caregivers from having to reinvent every wheel."

Memory Cafes: Memory Cafes offer a support group type setting in which persons with memory loss can share fun and laughter with their care partners and friends in a setting free from awkwardness and stigma. There is growing interest in these and pockets of them, or variations of them, are being offered in the state. The most active area seems to be in Asheville.

How important is it to guide caregivers in the appropriate use of respite care?

For some, it's intuitive or not welcome, for others, it's really helpful. The importance of guiding the way caregivers effectively use respite is underestimated. Reducing long-term care placement relies on caregivers being aware of their stress and guiding the use of respite so it truly is a break for caregivers. In nearly every survey, caregivers say they need more respite, but research shows that respite alone does not keep care recipients at home unless it's accompanied by education and support, used at appropriate times and doses, and that caregivers were satisfied with what they used their respite time for.

"Respite is not for helping a caregiver meet daily needs on an ongoing basis. That is a Band-Aid and we should instead be helping this person with case management and long term planning. Too many are using respite as daily in-home aide. One gentleman wanted help daily to get his wife up and out of bed because he could not lift her. This is a case where equipment and training is needed, not respite."

"Respite in conjunction with support and education really seems to work the best in the long run."

"Timing, dosing, frequency, intensity, flexibility and quality affect use and outcomes. By the time respite is needed, there is a need for many other community supports."

"Best use of respite may be to keep alive those aspects of life, activity, recreation, friendship, etc. that one wants to still be alive after the care receiver passes away."

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What are Employee/Employer issues around caregiving?

We repeatedly hear that employers need to provide flexible work time, time off for appointments, and reasonable job security for caregiver employees. Employees are often unaware of Family Medical Leave and how this applies to caregiving. The NC Lifespan Respite Project, led by DAAS and an advisory team of representatives outside DAAS, has goals for next year to focus on helping public and private employers know who their caregivers are and better assist them.

"Employee caregivers wish for flexible work, paid time off, and help from other family members."

"FMLA is a great start to help caregivers, but what happens when the time is exhausted? There should be more options for caregivers of dementia patients, like working from home, flex time, or even offering affordable adult day care options."

What are the most commonly unmet needs for caregivers?

In our services, we are most asked for respite and if there is a program to pay a caregiver to stay at home and take care of a loved one. The service they are often asking for but don't know how to put into words, is navigation assistance and someone to help them know what to do when, who to contact, how to pay for things, how to get family members to help them, how to not feel so overwhelmed, and how to keep straight who we all are and what we do and who they have already tried to get help from.

"Most of the time 1:1 education and problem solving of individual needs is what they need the most but don't realize."

"Early education for people on what Medicare does and doesn't cover, long term care insurance, etc."

"Respite"

"Help discussing supports that person may have within the family. If a caregiver has siblings or others that are helping, maybe they need help coming up with a schedule, communication, or a plan for self-care. We should be helping the family, not supplanting other resources, but including the family as a resource."

"Help with caregiving, help with respite, help with everything. Education is our only weapon."

"We need more education that Alzheimer's is a terminal disease."