

My Loved One Has Dementia; Is In-Home Care An Option?

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Caring for a loved one who is experiencing some level of dementia can become an overwhelming responsibility for any family member. There is no scholarly approach or analytical research that can provide answers to the questions about the road ahead that will tug at our hearts in a profound way. Decisions can only be made after you have information, guidance and support from a variety of resources. This article is a “Home Care and Dementia 101” course to help you begin this journey. The links provided to various resources can help “peel the onion” for those areas of particular interest based on your family circumstances.

What do I need to know about caregiving and dementia?

According to the *2021 Alzheimer’s Disease Facts and Figures*,¹ the number of individuals with Alzheimer’s will increase from 58 million in 2021 to 88 million by 2050. In Delaware the number of people 65 and older with Alzheimer’s is noted at 19,000 in 2020 and this number is projected to increase to 23,000 by 2025. Studies indicate that individuals with Alzheimer’s live an average of 4-8 years after diagnosis and it is possible that many will live as long as 20 years.

Approximately two thirds of dementia caregivers are women, 30% are age 65 or older; over 60% are married; over one half of caregivers are providing assistance to a parent or in-law with dementia. About 10% of caregivers provide help to a spouse with dementia. Approximately one quarter of dementia caregivers are those of the “sandwich generation” i.e., caregivers that are caring not only for an aging parent, but also for a child.²

This range of life expectancy means that the advancement of the disease can be a slow and uncertain progression leading to uncertainties as to the level of care that will be needed. Help may begin as “once in a while” assistance and then possibly escalate to 24/7 care over the period of years, which can be a difficult road map to manage. For family members providing the care, it may also impact their finances as well as the financial security of their loved one.

83% of the help provided to older adults comes from family members, friends and other unpaid caregivers. Nearly half of all caregivers (48%) who provide help to older adults do so for someone with Alzheimer’s or another dementia. More than 11 million Americans provide unpaid care for people with these diseases. In 2020, caregivers of people with Alzheimer’s or other dementias provided an estimated 15.3 billion hours of informal (unpaid) assistance valued at \$256.7 billion. 70% of the lifetime cost of care is borne by a family of caregivers in the forms of unpaid caregiving and out of pocket expenses. In Delaware, the

number of unpaid caregivers of those with dementia is 46,000 and the hours of care equate to 67 million which is a total value of unpaid care of \$1,141,000,000.²

My loved one is being discharged from a hospital or rehabilitation facility. What now?

When your loved one is discharged, you and/or designated family members will be invited to a planning meeting with a team of professionals. The team will likely include a Social Worker, Physical Therapists (PT) and Occupational Therapists (OT), a nurse who is familiar with the patient, and a representative from a home care agency you may have selected to support the caregiving needs. Hospice may be involved if appropriate, and the doctor will have provided information to the staff prior to the meeting. The discussion will include personal care needs, PT and OT that may be provided in the home, and the need for durable medical equipment. The discharge team may recommend 24/7 care in the beginning, with the understanding that the hours can always be reduced. The goal is to be certain that the discharge plan will result in maximum safety for the patient until your loved one is reacclimated to the home environment.

It is important to let the hospital or facility know if family members will be providing the needed care, since that will impact whether this person can be safely discharged. You also need to know if your loved one is sleeping throughout the night, if there are any new behaviors you need to be aware of, and if the care team thinks that your loved one can be left alone for any period of time. These are important questions since they will determine if the family can handle the caregiving on their own. If you do decide that help will be needed from a professional home care agency, it is best to plan in advance of the discharge. Regardless of the decision, having a plan is what is important. As Benjamin Franklin said, "If you fail to plan – you are planning to fail." Planning is everything and it is wise to be educated about all your options.

What do I need to know about the qualifications of a professional caregiver?

There are more than 100 licensed home care agencies in Delaware, encompassing different levels of licensure. Most home care agencies are licensed as Personal Assistance Services Agencies (PASA), which employ Direct Care Workers to provide non-medical assistance. They may employ Certified Nursing Assistants or Home Health Aides, but it is not a license requirement. Home Health Aide-Only (HHAO) and Skilled Care licensed agencies only employ caregivers who have completed Home Health Aide or Certified Nursing Assistant training prior to their employment with the agency or have been employed by a Delaware facility overseen by Registered Nurses. Skilled Care agencies also employ therapists and Nursing staff (RN, LPN) to provide a higher level of medical care in the home. Hospice agencies also can provide aide and nursing care in the home among other services. For a complete list of licensed agencies visit <https://www.dhss.delaware.gov/dhss/dhcq/ohflcmain.html>

Dementia specific training is an annual requirement for all Delaware agencies. It must include the following:

- Communicating with persons diagnosed as having Alzheimer's disease or other forms of dementia;

- The psychological, social, and physical needs of those persons; and
- Safety measures that need to be taken with those persons.

Other considerations when selecting a homecare agency include:

1. How many caregivers will be assigned to my loved one?
2. Can I meet a caregiver ahead of time prior to having services?
3. What if I do not like the caregiver that you send to my home for assistance?
4. What happens if a caregiver calls out sick or does not show up for the scheduled shift?
5. What services are you able to provide according to your license? What can you not do?

What can I expect professional caregivers will do during the hours they are providing care?

As for any client, caregivers can assist with Activities of Daily Living (ADLS) and Instrumental Activities of Daily Living (IADLS). The ADLS include help with personal care such as toileting, bathing, dressing and mobility supervision. The IADLS may include everyday tasks such as laundry, meal preparation, light housekeeping, and errands. For clients with dementia, there is also a component of continually managing the behaviors of the disease, such as wandering, agitation, and anxiety, among others.

Caregivers who have dementia training understand how to keep a client engaged in conversation and cue them through the steps of the activity to be performed. They know how to manage unpredictable behaviors through redirection in order to accomplish tasks at hand, and keep both the client and themselves safe.

Most important for the dementia client is overall engagement. Caregivers should understand what is meaningful to your loved one so that they are engaged. Engagement is different for every person and you want to be certain that the care plan meets your expectations and is appropriate for your loved one. It is helpful to develop an inventory about your loved one so that everyone who interacts with them knows something about them. Write things down that you want a caregiver to know about your loved one. An “About Me” document can include such things as your loved one’s favorite foods/snacks, hobbies, TV shows, games, places to visit, favorite clothing items, names of best friends, music they like, etc. When helping a client with dementia, knowing these types of things can help provide a roadmap for the caregiver so that they can more effectively interact with your loved one.

What community resources are available and how do I integrate them into the care plan?

We are fortunate in Delaware to have many community resources to help caregivers and their loved ones who suffer from dementia. Here are a few that you can research further based on interest.

The Alzheimer’s Association provides information and support to people impacted by this disease. Services include information on caregiver support groups, caregiver training, newsletters

and devices and programs to assist with the challenges of wandering. They also staff a 24-hour helpline (1-800-272-3900). The Delaware Valley Chapter has an office in Wilmington and Georgetown. <https://www.alz.org>

The Swank Center for Memory Care and Geriatric Consultation at Christiana Care is a comprehensive outpatient clinic for assessment of patients with neurocognitive disorders. The Swank Center's clinicians are also a helpful source of resources for families of people with dementia. The professional staff works closely with primary care providers and additional specialists to develop an optimal plan for care. The Swank Center's mission is to be a source of support for patients, their primary care treatment team, and family caregivers. More information can be found at <https://www.christianacare.org>

Jewish Family Services of Delaware provides mental health counseling and support services to individuals and families within the community; their services are available to everyone, regardless of background, to ensure equal access to high quality support and resources. The JFS COMPASS program is an outpatient dementia care and caregiver support program providing personalized, comprehensive care planning and hands-on care management to meet the medical *and* social needs of patients *and* caregivers. Their interdisciplinary team collaborates with other professionals to help patients and their caregivers navigate their journey with dementia. For more information, visit <https://www.jfsdelaware.org/compass>.

Easterseals Delaware & Maryland's Eastern Shore offers education programs and support for family caregivers. They can provide Adult Day Care for those with early stages of dementia and can provide connections to state agencies and other community providers. At the main campus, there is an assistive technology room that displays many different items to help a loved one suffering from dementia at various stages. Their staff can provide information on where to buy the items and can also help with financing when needed. <https://easterseals.com/our-programs/adult-services>

Delaware Health and Social Services (DHSS) provides links to numerous support services available to Delawareans, one of which is an Alzheimer's Toolkit. The Toolkit contains links to resources for Alzheimer's signs and symptoms, treatment, and research among others. https://dhss.delaware.gov/dhss/dsaapd/alzheimers_toolkit.html

A comprehensive list of State resources is available through the Delaware Aging and Disability Resource Center. Many families look to Adult Day Centers or Senior Centers to provide opportunities for their loved one with dementia to socialize, while the family caregiver can get a little break. Families can search for such services in addition to many others such as: food programs, legal assistance, financial coaching, caregiver support, emergency response systems, specialized equipment, transportation, respite care and in-home care providers. <http://www.delawareadrc.com/>

Families may also want to consider learning about the qualifications for the Medicaid Waiver program which can help with the cost of in home and facility care. It is important to note that Delaware is one of the few states that has no waiting list for Medicaid Waiver programs. To gain further information about qualifications and to start the process call: 302-451-3660. <https://assist.dhss.delaware.gov/>

Geriatric Care Managers can also be a great resource for families. This professional is usually a licensed nurse or social worker who specializes in geriatrics, and they can help navigate the steps

of the journey. They can be the “quarterback” and help with some of the decisions that may have to be made along the way. This is particularly helpful since they know the resources in the community and they know how to collaborate with the health system, which can include the hospitals, doctor office, facilities and rehabilitation centers. Their services are also helpful when there are many family members who may live out of state and they need someone to help with the overall coordination of a care plan.

<https://www.agingcare.com/local/geriatric-care-managers/de>

<https://www.aarp.org/caregiving/basics/info-2020/geriatric-care-manager.html>

<https://www.nia.nih.gov/health/what-geriatric-care-manager>

What are the advantages of making it possible for my loved one to remain at home?

For the patient with dementia, being at home in a familiar environment is less disorienting and can offer security and peace of mind. They also have a better chance of continuing to follow their routine, which is important in the overall care plan. Maintaining routines like the ones they followed before dementia behaviors truly “set in” can help reduce anxiety and confusion.

In-home care can provide as much or as little assistance as a family requires. Family members often want to be just that: a wife, a daughter, a husband, and not a caregiver. Working with professional home care providers affords them the opportunity to be that family member, all the while keeping their loved one safe and happy in their own environment.

Support at home can help delay the move to long-term care facilities, but the progression of dementia may eventually require higher levels of care and 24/7 supervision. The timing of a decision to consider options outside the home may depend on the ability of the family, private or professional agency caregivers to manage the potentially unsafe behaviors that often accompany the disease.³

What are some of the challenges that my loved ones and caregiver will face?

Dementia is a disease that slowly progresses, and as previously stated, statistics tell us that a person can live from 4–8 years, but can also survive 20 years with the disease.¹ The level of care can change from occasional visits and phone calls to your loved one not being able to be left alone. So, bottom line – responsibilities will increase as the disease progresses and the caregiver stress level will most likely also increase.

One of the biggest challenges is that adult children may not be able to provide the level of care that is needed. It is one thing to pay bills – it is another thing to assist a loved one with toileting. Some children may find this to be a very difficult task because of the intimacy involved. This is when dignity begins to decline for your loved one. If you have moved your loved one to your home, it also means less privacy for you and your family members. Whether their own home or your home, there may also be modifications that must be made at the home to accommodate them, e.g., ramps, hospital beds, bathroom modifications, chair lifts, etc.

If there are children in the home, it is important to have a conversation with them, because they may not understand what is going on with their loved one. Family members also need to

communicate with each other, and it is probably best to have one person who is the main contact for different aspects of the care so that there are not too many cooks in the kitchen.

The biggest challenge is going to be knowing when to ask for help. You want to get help before burnout, or something happens that you are not trained to handle. There can be physical changes that are a new challenge – like transferring your loved one from the bed to a wheelchair. If they cannot bear weight on their own feet, the transfer may mean that someone is going to get hurt because the transfer is not safe. There can also be behavioral changes, which may include more aggression or combativeness. It is important to discuss these changes with the physician and seek advice.

At what point do I consider moving my loved one to a facility?

When 24/7 care becomes necessary, it may be the tipping point for having new conversations with the doctor. If a caregiver is an only child, one cannot stay up for 24 hours to provide care. Professional in-home caregivers can help support the family caregivers and relieve some of the burden of the 24/7 supervision. Making a decision to move your loved one to a facility is not going to be easy, and it is best to gather information early in the process. You will want to learn about the services provided in the Assisted Living area (as opposed to the Memory Care area) and understand the qualifications for each. If you must move quickly, placement will depend on availability, and it might mean you cannot place them in your first choice of a facility. That is why it is important to gather information ahead of time.

The facility, the doctor, your home care agency professionals you might have engaged to assist with care, support group members, as well as personal clergy are all potential resources to support you as you take this important step.

How do I further support my loved one if they do move to a facility?

During the recent pandemic, this was certainly a challenge, and many families and their loved ones suffered because of the lack of connection. It was hard enough for those without dementia – having cognitive issues presented a different level of stress for the loved one and their family members who could not visit.

During normal times, it is helpful to establish a routine – a plan of visitation, and perhaps keep a large calendar in your loved one's room so that they can see the plan for every day. They may not remember, but you can use pictures/leave a sign each day letting them know who is visiting. As in the home environment, routine and structure are important. The idea is to develop a plan just as if they were home. This lets everyone know what is expected and defines the amount of time that will be spent. If possible, it would also be good to take them out of the building and go for ice cream, go for a ride, or go to lunch. Perhaps just take a walk outside. But the main point is to have a plan and have anyone who is going to visit or interact with your loved one become involved in the plan.

What's the important message?

The dementia journey is unique to each person who is challenged by this terrible disease, and every family member will have their own feelings of how to deal with this reality. There are no answers that will perfectly fit every situation. Making the commitment to handle the in-home care for your loved one will be a growth experience for all involved, and when managed with

care, the love that is shown and experienced by your loved one will matter. There is a good chance that the family will also become closer, as long as the challenges are met with reason and support is asked for when needed. At the same time, everyone will benefit if there is an honest conversation about whether home care can safely continue when the disease progresses into care that may or may not be manageable. Having support to help you at this critical time in the decision-making process is important for all concerned. We are all seeking peace of mind hoping that we made the right decisions along the way. That is possible when we lead with our heart and couple that with professional advice.

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