

A Guide *to* Hospice *for* Dementia and Alzheimer's Disease



Discover how hospice care for dementia and Alzheimer's patients can help to improve quality of life and offer invaluable support for loved ones.

ST. CROIX[®]
HOSPICE

A Guide *to* Hospice *for* Dementia *and* Alzheimer's Disease

Discover how hospice care for patients with Alzheimer's and dementia-related disorders can help to improve quality of life and offer invaluable support for loved ones.

St. Croix Hospice Chief Medical Officer
Andrew Mayo, M.D.

Sponsored by

ST. CROIX[®]
HOSPICE

To learn more, contact us at:

info@stcroixhospice.com

855.278.2764

stcroixhospice.com

When most people think of hospice, they think of palliative or end-of-life care. While these are two aspects, hospice care is more than that. Hospice care improves the quality of life for people who have advanced, life-limiting illnesses by providing pain and symptom management, nursing care, emotional support and more. Although cancer remains the leading diagnosis for hospice enrollment, more and more patients with Alzheimer's and dementia-related disorders are being admitted to hospice. Dementia is a general term for memory loss and cognitive impairment severe enough to interfere with a person's daily life. Other dementia-related disorders can include Lewy body dementia, frontotemporal disorders, and vascular dementia. Alzheimer's disease is the most common cause of dementia. In addition to memory loss, Alzheimer's and dementia symptoms include misplacing items and difficulty completing familiar tasks. As dementia-related disorders progress, patients may also have trouble communicating.

Once a patient is eligible, hospice care can be effective in addressing the needs of individuals with Alzheimer's or dementia. Programs like St. Croix Hospice's North Star Dementia Care Program increase safety for hospice-eligible Alzheimer's and dementia patients, families and caregivers. They also provide expert advice, tools and support that enable families and caregivers to proactively manage symptoms of Alzheimer's and dementia.

If you or a loved one has Alzheimer's or dementia and are considering hospice care, you probably have a lot of questions. Here's what you need to know about hospice for dementia patients.

What are the *challenges* of caring for a loved one with dementia?

Thanks to improvements in medicine and public health efforts, the general population in the United States is getting older and living longer. The number of Americans age 65 and older is projected to reach 94.7 million by 2060. However, this also means the number of people with Alzheimer's or dementia will increase. According to the Alzheimer's Association, about one in nine people age 65 and older have Alzheimer's or dementia. There are an estimated 6.3 million people currently living with Alzheimer's or dementia, and that number is expected to increase to 13 million by 2050.

As more people are diagnosed and live with Alzheimer's or dementia, family members and friends often become the primary caregivers. But it's not an easy role to play. According to the Alzheimer's Association, compared with caregivers of people without dementia, twice as many caregivers of those with dementia experience significant emotional, financial and physical impacts.

Family members and caregivers often have to deal with a lot of difficult behaviors from their loved ones. This may include aggression, wandering or refusal to eat. Family members also have to make tough decisions around end-of-life and cope with the stress of caregiving. But help is available for those who need it. Hospice care provides many resources that families might not have access to on their own. It also increases the safety of patients, families and caregivers.

Putting a loved one with Alzheimer's or dementia on hospice can be an emotional decision. Many caregivers feel guilt or regret. They may feel like they could have done more to help their loved ones. There are also many myths about hospice care that may discourage families from seeking it out. But once someone is eligible for hospice, it is often the best option for everyone involved. Learning more about hospice criteria for Alzheimer's and dementia as well as what resources are available to hospice patients can ease caregiver concerns.

What is *hospice care*, and how does it work?

Hospice focuses on the care, comfort and quality of life for people with terminal illnesses. At a certain stage it may no longer be possible to cure the illness. The patient may also choose to stop receiving treatment. When someone enters hospice, they are choosing to no longer pursue curative treatments, and a physician has determined they have six months or less to live.

A hospice care team consists of several specially trained healthcare providers including:

- Doctors
- Registered nurses
- Dietitians
- Home health aides
- Social workers
- Occupational therapists
- Music and massage therapists
- Chaplains

Family members are usually heavily involved in care as well.

Hospice is available to patients with a life expectancy of six months or less. This doesn't mean the patient or their family is "giving up." It means the focus is shifting from curing the disease to enhancing a patient's quality of life by meeting their physical, social and emotional needs. Hospice providers who have expertise in Alzheimer's and dementia can help family members understand what to expect in the final stages. But most importantly, hospice gives patients the opportunity to live their last days with expert care and support.

What are the *signs and symptoms* of Alzheimer's disease?

Alzheimer's disease is the most common form of dementia, and its symptoms can vary from person to person. However, memory loss is usually one of the first signs of the disease. Someone with Alzheimer's might also have trouble finding the right word during conversations.

According to the Centers for Disease Control and Prevention (CDC), there are 10 warning signs and symptoms of Alzheimer's:

10 WARNING SIGNS AND SYMPTOMS of Alzheimer's

1

Memory loss that disrupts daily life

2

Challenges in planning or solving problems

3

Difficulty completing familiar tasks

4

Confusion with time or place

5

Trouble understanding visual images and spatial relationships

6

New problems with words in speaking or writing

7

Misplacing things and losing the ability to retrace steps

8

Decreased or poor judgment

9

Withdrawal from work or social activities

10

Changes in mood and personality

It's essential to be able to tell the difference between the symptoms of Alzheimer's disease and typical age-related changes. Memory loss that disrupts daily life is not a typical part of aging. With age-related changes, someone might have trouble remembering a name or date but figure it out later. With Alzheimer's, especially in the early stages, people may forget recently learned information and ask the same questions over and over.

What are the *stages* of Alzheimer's disease?

Alzheimer's disease usually progresses slowly through three stages: early, middle and late. However, Alzheimer's-related brain changes can start years before there are any signs of the disease. This is known as preclinical Alzheimer's, and the symptoms aren't noticeable.

Early-stage Alzheimer's

In the early stage, a person with Alzheimer's can still function independently. They can perform daily tasks such as driving or going to work. The symptoms may not be very noticeable, but a person may start to feel like they are having memory lapses.

The earlier someone is diagnosed with Alzheimer's or another dementia-related disorder, the more opportunities there are for treatments and interventions.

Middle-stage Alzheimer's

This stage can last for several years. Alzheimer's symptoms become more pronounced as time passes. The person can perform daily activities with assistance, but they may behave in unexpected ways. They may forget information about themselves, like their address or phone number. They may become restless and have an increased tendency to wander.

Late-stage Alzheimer's

In the last stage, Alzheimer's symptoms are severe, and individuals may need round-the-clock assistance. They may also:

- Lose awareness of recent experiences and their surroundings
- Have changes in physical abilities, such as walking, sitting or swallowing
- Have trouble communicating
- Become vulnerable to infections

Late-stage Alzheimer's disease is usually when caregivers seek support services, such as hospice care. However, life expectancy can be difficult to determine. This can make it difficult to make the decision to start hospice care. On average, a person with Alzheimer's lives four to eight years after diagnosis. Some may live as long as 20 years.

Benefits of *hospice care* for dementia patients

Caring for a loved one with advanced Alzheimer's or dementia can be very difficult. In the end-stage of dementia-related disorders, patients may not be able to walk by themselves. They may also start having serious infections like pneumonia or kidney infections.

Sometimes, patients and their families aren't aware hospice care is an option. Or they might wait too long after receiving a terminal diagnosis to seek hospice care. But there are benefits to starting hospice as soon as a patient is eligible.

Creating a support system

One benefit of hospice care is that it provides patients and their families with a highly trained support system. Being a caregiver can often be very isolating. Choosing hospice means you're not alone in your caregiving journey. You'll have a team of professionals who can help ease some of the workload. They are there to support you during the end of life and provide bereavement support after the death of a loved one. That can come in the form of phone calls or in-person visits, grief support communications or support groups.

Ensuring responsive care

Another benefit of hospice care is that hospice providers can pick up on subtle changes family members might not notice. This is especially important in late-stage Alzheimer's and dementia since patients may not be able to speak for themselves. Patients may not be able to verbalize or otherwise communicate pain or other issues. Since hospice provides an individualized approach to care, providers are in tune with what is normal for the patient. They are able to intervene quickly if something seems off.

Higher quality of life

Choosing hospice as early as eligible is beneficial for improving the quality of life for patients and their family members. In addition to clinical and medical care, hospice patients can receive different types of therapy. Music therapy, for example, can help hospice patients feel more relaxed or happy. Physical and occupational therapists can help patients maintain their functional abilities and provide strategies for pain control and relief.

Although hospice no longer focuses on curing the disease, it does treat the symptoms of the disease. The hospice care team can help manage and alleviate some of the more challenging symptoms of Alzheimer's and dementia. They can help manage additional conditions the patient might have.

There is also evidence that hospice improves care and quality of life for patients with dementia-related disorders in their last months of life. A 2022 study found that hospice patients with dementia are more likely to receive excellent care and have their sadness and anxiety managed than patients without hospice. Patients on hospice were also less likely to be switched to a different care setting in the days before their death.

Emotional and spiritual support

Another benefit of hospice for Alzheimer's and dementia patients is the emotional and spiritual support. It's extremely important to maintain emotional and spiritual well-being in the patient's remaining days. Spiritual care is offered to all hospice patients, no matter their faith or belief system. Although patients with Alzheimer's or dementia may not be able to communicate, research has found that rituals and music can be therapeutic in severe dementia. There is also evidence that emotional support can be beneficial for overall wellbeing.

Advance care planning

Finally, hospice can help patients and families with advance care planning. This can take a lot of stress off of family members. Sometimes, we think we know what our loved ones want, but we may get it wrong. An advance care plan helps prepare families for future decisions. This includes instructions for medical care if the patient cannot communicate their own wishes. The plan can give patients with Alzheimer's or dementia a sense of control during a period of uncertainty. These decisions should be made as early as possible. As Alzheimer's or dementia progresses, patients may not be able to remember what decisions they want to be made.



Choosing *hospice* for Alzheimer's and dementia patients

Choosing hospice care can be overwhelming for patients and their families. There are a lot of different factors to consider. For example, what are the patient's end-of-life wishes? What needs does the caregiver have? And how can you be sure you're choosing the right hospice agency?

These questions are completely valid and normal to ask. Although hospice care can be stopped at any time, you still want to make sure you're making a good choice. There are many different questions you might want to ask as you're deciding on hospice care. Here are a few examples:

What do others say about this hospice?

References and reviews can be extremely helpful when it comes to choosing hospice care. If you know someone who has used the hospice agency you are considering, ask them what their experience was like. Would they recommend it to others? Why or why not? You might also want to ask your loved one's healthcare providers their opinion.

Is the hospice accredited?

Although accreditation isn't required for hospice, you may want to consider finding one that is. Non-accredited hospice can be just as good, but accreditation means it has been evaluated by a third party.

Can it meet your specific needs?

You and your loved one are likely to have many questions and concerns. It's important to feel confident that the hospice can address those concerns. If there is anything you think the hospice staff needs to know in order to provide the best care, make sure you bring it up.

How long is dementia hospice life expectancy?

Although patients must have a prognosis of six months or less to live to qualify for hospice, some patients live longer. Patients must be reassessed for eligibility at regular intervals but there is no limit to the amount of time they can receive hospice care if they continue to be eligible.

Is it time for *hospice*?

Patients with dementia, as well as their families, face many unique challenges. Although family members might do the initial caregiving, they often need more support as the disease progresses. Despite myths and misconceptions about dementia and hospice, it is often the best choice for patients and their families.

Still, it's not an easy decision to make. After all, family members may feel like they know their loved one best and can make decisions for them. They may also feel guilty about not being able to handle the demands of caring for a sick loved one. Hospice can ease a lot of the stress family members feel while ensuring that their loved one remains comfortable in their last days.

Signs that indicate it could be time for hospice:

- Noticeable health declines or significant pain
- Frequent hospitalizations or ER visits as a result of falls or other accidents
- Changes in comprehension, progressive weight loss or an increased number of infections or wounds

If you notice one or more of these signs in the past year, you may want to request a hospice referral. It's okay to feel unsure about whether hospice is the right next step, and the eligibility process can be hard to navigate without help. Scheduling a consultation with a local hospice provider can help determine if it's time for a hospice assessment.



What are the *criteria for hospice* for Alzheimer's patients?

If you or a loved one decides it's time to start hospice care, you may be wondering about eligibility. Not all patients with Alzheimer's or dementia qualify for hospice, which is why it is important to consult with a hospice agency to determine if and when hospice care might be an option.

Hospice care is covered by Medicare, Medicaid, and most private insurance. According to the Centers for Medicare and Medicaid Services (CMS), a patient who receives Medicare Part A can get hospice care benefits if:

- They get care from a Medicare-certified hospice.
- They are certified as terminally ill by their attending physician and/or hospice physician.
- Their prognosis to live is six months or less if the illness runs its normal course.
- They sign an election statement to enroll in hospice. Signing the election statement means the patient gives up their right to use Medicare to pay for curative treatment. Instead, payments are redirected to cover the services provided by the hospice team.

To meet hospice eligibility criteria for Alzheimer's or dementia, patients must experience multiple declines in physical and mental performance due to the illness. The Functional Assessment Staging Tool (FAST) is used to assess functional status in people with dementia-related disorders. To be eligible for hospice, patients with Alzheimer's or dementia must be at or beyond stage 7. They must:

- Be unable to walk, dress and bathe without assistance
- Have urinary and fecal incontinence (intermittent or constant)
- Have no consistently meaningful verbal communication (stereotypical phrases only or the ability to speak is limited to six or fewer intelligible words)

They must also have at least one of the following medical conditions:

- Aspiration pneumonia, which occurs when food or liquid is breathed into the airways or lungs instead of being swallowed
- Kidney infection
- Blood poisoning
- Bedsores
- Recurrent fever after treatment with antibiotics
- Inability to maintain sufficient fluid and caloric intake with 10% weight loss in the past six months or serum albumin less than 2.5 g/dL

Diseases such as cancer, diabetes, hypertension or congestive heart failure create additional considerations for hospice eligibility. Many patients with Alzheimer's or dementia have other conditions as well. If you think your loved one might qualify for hospice you can request a consultation at no charge. This can help ease any doubts or fears you might have about the decision.

By choosing hospice, many people feel they are able to provide the best quality of life for their loved ones. Hospice acts as a primary care provider and helps patients stay out of the emergency room or hospital. Hospice supports comfort and safety for patients during the time they have remaining.

If it's time for you or a loved one to enter hospice, consider St. Croix Hospice. Our North Star Dementia Program specializes in providing care tailored to the needs of hospice patients diagnosed with Alzheimer's or dementia. St. Croix Hospice staff are industry experts in Alzheimer's and dementia care, with our staff holding dementia care certification through the Crisis Prevention Institute. You can rest assured that you or your loved one will receive expert care and coordinated treatment with a focus on safety and quality of life. To learn more about the St. Croix Hospice North Star Dementia Program, stcroixhospice.com/northstar.

A Guide *to* Hospice *for* Dementia *and* Alzheimer's Disease

Sponsored by

ST. CROIX[®]
HOSPICE

To learn more, contact us at:

info@stcroixhospice.com

855.278.2764

stcroixhospice.com