



# THE ALZHEIMER'S PATIENT AND HOSPICE CARE

Provided by Florida Hospice and Palliative Care Association in partnership  
with The Alzheimer's Association Chapters of Florida

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## About Alzheimer's

More than six million Americans are living with Alzheimer's disease; most are over age 60. The older one gets, the greater the chance of developing Alzheimer's disease. Research is making progress, but the cause is not yet known and there is no cure. Alzheimer's is the fifth-leading cause of death in the United States for those 65 and older, killing more than breast cancer and prostate cancer combined. By 2050, the number of people 65 and older with Alzheimer's is projected to reach 12.7 million. The number of Americans that die each year from Alzheimer's and other dementia deaths have increased 16% during the COVID-19 pandemic. There is a higher prevalence of Alzheimer's in older Black and Hispanic Americans than White Americans. The disease was discovered in 1906 by a German pathologist but has become a more worldwide concern because we are living so much longer. Alzheimer's disease is the most common form of dementia. In the late stage, Alzheimer's and vascular dementia or other related disorders have similar symptoms and effects. With Alzheimer's disease, brain cells die, and the person loses memory, reasoning, judgment, and thinking skills. By supporting remaining abilities, we can help the individuals and family caregivers manage these losses, but eventually there is a need for effective end-of-life care and support.

## The Person with Alzheimer's

It is important to remember that persons with Alzheimer's and other dementias have led full and interesting lives, even though at the end-of-life they may appear so distant and unresponsive. Having the family share stories of the person, or read a short biography of the person's life, may help to bring the actual events and facts alive for hospice workers. Knowing what was important to your patient, or thinking about the history the individual lived through, may help you to relate to the person better at this important time of his life.

## Advanced Alzheimer's

Hospice programs in Florida treat patients with every kind of terminal condition and many different forms of dementia, including persons with Alzheimer's disease. The hospice approach to end-of-life care is holistic and addresses the needs of the person and his or her caregivers and family in a comprehensive and team-oriented manner. This is especially important to the family of a person with Alzheimer's disease, since this person may have difficulty communicating his or her needs to family members. More than those with other diseases, these patients spend a long period at the end of their lives bed bound, mostly unresponsive, and in need of total care. As with all patients, it is the goal of the hospice program to keep the dying patient comfortable while supporting and comforting family and loved ones regardless of the setting or the patient's daily abilities. These communication challenges become part of the task of the hospice worker.

At the end stage, a person with Alzheimer's will spend a lot of time sleeping. This may be interrupted by aimless activity, they may sometimes be frenzied, and voice sounds that may resemble moaning or crying. There will usually be weight loss and the need for complete bowel and bladder care. The person cannot express needs in any usual way. These extreme care needs may be devastating to caregivers, and hospice workers must be prepared to assure the safety and comfort of the patient while supporting caregiving families through the last phase of this incurable disease. As with all hospice patients, persons with Alzheimer's and other dementias need social and spiritual support. It is the task of the interdisciplinary team to make sure that all such needs are addressed, even though feedback on effectiveness may be non-existent.

# The Family Caregiver

Families and friends (11.2 million unpaid caregivers) provide over 80% of all care for persons with Alzheimer's disease. Most families will have been providing care for many years by the time the loved one is in the final stage of Alzheimer's. Caregivers can tell us so much about how to help the patient. These caregivers have often changed their lives because of the needs of the person with Alzheimer's disease and other dementias. By respecting and appreciating family caregivers, we can help them accept the approaching death and their own grief and loss. Family caregivers must observe and manage many of the same problems as with other dying patients: the loss of appetite, staying in bed, unable to provide any self-care, curling into a fetal position. However, in dementia patients this is made more difficult by the fact that they often cannot verbally communicate needs. The caregiver may be frustrated and uncertain. The hospice worker has a responsibility to advise and support the caregiver's efforts and recognize there is often "burnout" and exhaustion in these families. Caregivers not only suffer emotionally but also physically. Family caregivers report high levels of stress because of the prolonged duration of caregiving, and 30-40% report symptoms of depression. The prevalence of anxiety is 44% among dementia caregivers (Alzheimer's Association 2021: Facts and Figures). Supportive help is critical.

## Communication

Those who have Alzheimer's disease will often have many years of slow decline due to brain changes from the disease. Yet, persons with Alzheimer's disease often retain social skills quite far into the illness. Communication is critical at all stages, even at the end. Here are some communication tips for the later stage:

- Say who you are
- Speak slowly and clearly
- Singing is communication
- Repeat the same message often
- Read to the patient
- Use the person's name
- Use simple words & phrases
- Don't ask questions
- "Being with" is communicating
- Get close - touch if appropriate
- Don't expect an answer
- Don't talk about or over the person
- Music and tactile objects foster comfort

## Hospice Care and Alzheimer's

Hospice is a very helpful choice for both the person with Alzheimer's disease and their families because it provides the very kind of care that is most important - comfort, freedom from pain, a "high touch approach." Persons with Alzheimer's and other dementias can be enrolled in hospice care wherever they live - either at home or in a nursing facility. Criteria for hospice enrollment for persons with end-stage dementia may not always be well known - the issues of mobility, nutrition and weight, verbal communication, problems with infection and overall decline are evaluated. The physical support provided by hospice teaching and supportive equipment can greatly relieve the family caregiver. Social support provided by hospice adds additional compassion to the dying experience. And spiritual support is critical for both the patient and the family.

The Alzheimer's Association Chapters in Florida are available to families as a resource for education and support throughout the continuum.

Central and North Florida: (407) 951-7992

Florida Gulf Coast Chapter: (727) 578-2558

Southeast Florida Chapter: (954) 786-1533

24 Hour Helpline – (800) 272-3900

<https://www.alz.org/alzheimers-dementia/facts-figures>



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### **Florida Hospice and Palliative Care Association**

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