Facing the end of life (as it has been known), is a very individual experience. The physical ailments are also experienced uniquely, even though the conditions are typical and confront many other people. Family circumstances, dynamics, and philosophies are different.

Our organization meets the individual needs of patients with dementia who want to remain wherever they are currently living. Should the patient’s symptoms become too problematic to manage there, our organization has the option of inpatient care.

As dementia progresses, a common problem that occurs is the patients lose the ability to tell others what they need. Our individualized and comprehensive care anticipates and adjusts to this inability. We make provision for effective pain management, nutritious meals, adequate hydration, and appropriate skin care. We also take measures to avoid and to treat infections, and to prevent or to calm the patient’s agitation.

We (your hospice team) continually evaluate our patient’s status and update the plan of care as symptoms and conditions change. Our plan of care changes daily if that is what our patient needs. Our goal is for you or your family member to be
physically and emotionally free from stress, and to be comfortable and to maintain dignity.

Hospice serves patients and their families by giving support and resources that are tailored specifically for individual family’s needs. The compassionate care provided can include (but is not limited to) the services listed below:

**Personal consideration**

The hospice team listens to the patient and the patient’s family members. They learn about things like the patient’s likes and dislikes, habits, physical abilities and disabilities, and how different moods show through the patient’s behaviors.

**Patient advocacy**

The patient is the focus of the care, and the patient (and family) is advised, encouraged, and supported, accordingly. Our patient advocacy includes coordinated care. A personal plan of care developed for the patient, by hospice and the patient’s doctor, addresses every level of the illness.

**Physical comfort**

Hospice serves the patient and the loved ones by decreasing frequent visits to emergency rooms and repeated hospitalizations. It also offers the benefit of helping the patient to remain in the comfortable and familiar surroundings of home – whether that is in their personal home, a long-term care facility, or assisted living.

**Peace of mind**

Our organization takes care of you and your family with medical resources and support that are there whenever you need it. Our agency has the Telecare® program that ensures a nurse
is available by phone 24/7 to answer questions or, when needed, send a member of the team to the patient. Hospice coordinates and supplies all medications, medical equipment and supplies that are appropriate to your needs.

We also train family members how to care for their loved one routinely or until help arrives. The education and training of the family caregiver support the patient and the hospice team. It also contributes to keeping everyone calm.

**Emotional And Spiritual Well-being**

Hospice also helps the patient and the family to maintain emotional and spiritual well-being by providing spiritual and emotional support. Examples of this type of support include:

**Respite care**

“Respite” care that means that a hospice provider provides in-patient care so that caregivers can rest and relax. In-patient care units provide a comfortable, home-like environment for your loved one, and peace of mind for you.

**Financial assistance**

Medicare, Medicaid/Medi-Cal, and private companies cover hospice services. Sometimes, however, there are other money concerns created by the length or severity of the illness. Our social workers can help families with financial planning and locating financial help during hospice care and afterward.

**Quality of life decisions**

Eventually, the patients’ condition will progress closer to the end of life, or perhaps complications will become more frequent and more severe. Prior decisions about how much medical support is desired need to be reevaluated. These are difficult decisions that can be overwhelming, especially if
the decision is to stop medical intervention. Hospice is there to help.

Aftercare

Although the patient is gone, the team still serves the surviving family members. For up to a year after the death of the loved one, the hospice team walks through the grieving process with the family.

Does Your Family Need Hospice Support?

Are you or a loved one confronted with a terminal illness such as dementia, or Alzheimer’s disease, a form of dementia? If this illness is a part of your family now, you will probably need hospice because it serves those who are in the end stages of dementia. As mentioned, hospice is designed to improve the quality of the remaining life for the patient and the patient’s family by relieving pain, controlling symptoms, and reducing everyone’s anxiety and worry.

Dementia / Alzheimer’s Checklist

Dementia and Alzheimer’s disease are personal experiences. No one knows how long a particular stage or symptom will last, so it can be hard to determine when it is time for hospice care. When a patient is admitted to hospice care, life expectancy at that point is six months or less. That determination is for a doctor to make, but there are signs that the disease has progressed to the level of hospice care:
• The potential patient is unable to say more than a few words.
• The person no longer walks and may be bed-bound.
• Complete dependence on others to perform their activities of daily living, such as dressing, grooming, and feeding themselves.
• The potential patient seems very anxious.

What Happens Next?

If your loved one has the symptoms mentioned, you can request a hospice evaluation. The assessment is done by a physician, or an employee of a hospice agency to determine, among other things, the person’s need for:

• Pain management
• Symptom management
• Counseling regarding hospice or other care options

Your physician may also make this request although you do not need to wait for a doctor referral. You can call 1.866.41.our organization, to find out how hospice can help you.

Approaching Your Family about Hospice Care

If you are showing symptoms of dementia and want to plan for your future, letting your loved ones know can help formulate your plan. It can be an awkward conversation to have, but hopefully that won’t stop you. Because the final months are very emotional and filled with tough decisions, now may be the best time to talk about it.

First, you may want to educate yourself by researching the topic of dementia, Alzheimer’s disease, and hospice care. It would probably be useful for you to learn some of the common misconceptions about end-of-life care. This knowledge would
help you to answer any questions your family may have about hospice.

**Gathering Information**

Before talking to your family, find out what they know about your health, and clarify anything that they misunderstood or didn’t fully understand. If your loved ones are not emotionally prepared to hear the truth about your prognosis, perhaps you could have your physician, clergy, or close friend of the family talk to them too.

**Communicating Your Wishes**

An important part of the conversation is to listen to their concerns regarding moving forward. Then you could explain to your family that hospice care meets the goals that you have for the future. Explain that you are not giving up, that you are making plans that will benefit everyone. The focus for you is to live the remainder of your life comfortably, without pain, and in your home, without burdening the family. Your desire for them is to make their last moment(s) with you less stressful.

It is up to you to initiate this conversation and express your wishes. You may find that your family wanted to talk to you, but didn’t know how you would respond.

**Suggesting Hospice Care for a Family Member**
The time has come to discuss the future care of your loved one, and no one is talking. Here are suggestions to help you start the conversation (knowing that your family member is aware of the diagnosis and prognosis).

First, become more informed by researching the topic of dementia, Alzheimer’s disease, and hospice care. It would also be helpful for you to learn some of the common misconceptions about end-of-life care. Some of the misconceptions include:

- Hospice is only for those with a few days to live. In reality, hospice serves its’ patients and families for months.
- Using hospice services is a sign of giving up. Hospice is about a quality of life, not about giving up. A study of terminally ill residents in a nursing home showed that the hospice patients are substantially less likely to be hospitalized the final 30 days of life. 1 Miller SC, Gozalo P, Mor V. Hospice enrollment and hospitalization of dying nursing home patients. American Journal of Medicine 2001;111(1):38-44
- Choosing hospice means giving up your personal physician. This belief is not true. Your doctor becomes part of the hospice team that cares for you.
- Hospice care won’t let me or my family members make any decisions about my care. On the contrary; the patient and the family are at the center of hospice care. Patient care plans are developed to meet the needs and desires of the patient and the family.

Having this information would help you to answer any questions your family member might have about hospice.
Talking To Loved Ones About The Future

Now that you are more informed about hospice, how do you talk to your loved one who is showing signs of dementia progression, about the future? The answer is very lovingly. Start by asking their permission to discuss their care as the condition progresses. Inform the person that you want to make sure that they get the best care possible as the disease progresses, and that you want to know their priorities and desires. You could ask questions like:

- What are you hoping for as time goes on?
- What are you most concerned about regarding your illness?
- What are you most concerned about regarding your family?

A crucial part of the conversation is to listen closely to your loved ones’ concerns about moving forward. Then you could explain to your family member that hospice care has options that can honor their priorities and desires.

The Importance of Listening

If it falls to you to initiate this conversation, remember to be a good listener. Be aware that during the first conversation, there will probably be some resistance to talking about hospice care, and that’s okay. In future discussions, the topic will become less daunting as you patiently answer your loved one’s concerns.

Hospice Means Support

Hospice is available to you or your loved one wherever “home” is – nursing home, assisted living facility, family home, even a hospital. Hospice care delivers 24-hour service to meet your unique physical, spiritual, and emotional needs. Hospice care
is not about how you or your loved one dies. Hospice care is about how you and your loved one lives, right up to those last precious moments.

**Contact Harbor Light Hospice for Support**

Harbor Light Hospice can greatly improve the overall quality of life for Alzheimer/Dementia patients and their loved ones. To learn more about our supportive services, call one of our locations or [contact us online](mailto:contact@harborlighthospice.com) today.