Hospice Care Information

What is palliative care?
Palliative Care is different than Hospice Care. GetPalliativeCare.org states that Palliative Care “is specialized medical care that focuses on relief of the symptoms and stress of serious illness. The goal is to prevent and ease suffering and to improve quality of life for patients and their families. Palliative care is appropriate at any age and any stage of an illness. And, it can be provided at the same time as curative treatment.” To find a hospital that offers Palliative Care, search for your state on the Palliative Care Provider Directory of Hospitals.

What is hospice care?
Hospice is a special way of caring for people who are terminally ill (normally 6 months or less) by providing care and support for them and their families. Hospice provides physical, psychological, social and spiritual care to both the patient and the family, so you and your loved one can live each day to the fullest. The hospice program serves individuals with ANY terminal illness including Alzheimer’s disease or a related dementia. Hospice does NOT provide 24-hour care, but it assists the family in managing the individual’s care.

What is the primary goal of hospice care?
The primary goal of hospice care is to help the individual and his/her family to maintain the highest quality of life in the last stages of the illness; without the fear of dying in pain, alone, or without personal dignity. This includes managing pain and other symptoms of the illness rather than providing treatment for the illness. Emotional support for the individual and family is also provided.

Would a person with dementia qualify for hospice care?
If a physician determines that the person with dementia has a six month life expectancy (or less), then the family may be able to benefit from hospice services. A diagnosis of dementia alone does not qualify for hospice care. There needs to be another diagnosis/condition that affects life expectancy.

What services are typically provided by hospice care?
- Physician services
- Nursing care
- Counseling
- Inpatient care
- Medical appliances and supplies
- Prescription drugs
- Respite care
- Bereavement follow-up
- Massage, physical, occupational and speech therapists
- Home health aides
- Nurses
- Volunteers

Who provides the services?
A team approach is taken when hospice services are rendered. The team may consist of:
- Family members
- Physicians
- Social workers
- Home health aides
- Nurses
- Volunteers

Where can hospice care be received?
Hospice care can be utilized at home, in nursing facilities, assisted living facilities, or hospice centers. In some cases, it is also available in hospitals.
What expenses are involved in hospice care?
Medicare, Medicaid, and most private insurance companies provide 100% coverage of hospice services. The coverage may include the services listed above, as well as medical equipment, supplies, and medication related to the dementia. Most likely, there will not be any deductibles and only limited coinsurance payments. It is important to check with the hospice program for a full explanation of benefits.

What can someone expect when beginning hospice care?
Before the services begin, the hospice staff will meet with the physician(s) of the person with dementia and a hospice physician. The medical history, current medical status, and life expectancy of the person with dementia will be discussed. Following this meeting, the hospice staff will meet with the person with dementia and his/her family to discuss the hospice philosophy, services, and expectations. A care plan will be developed specifying pain and symptom management, equipment and medication needs, emotional support systems, and service to be used.

What are some important questions to ask a hospice program?
- Will you accept a patient that has been diagnosed with Alzheimer’s disease (or a related dementia)?
- What are the admission and eligibility requirements of the program?
- What are the family caregiver’s responsibilities in the program? Are they given the information and training they need to care for the patient at home?
- What responsibilities of management and care will the hospice itself assume?
- Medicare and/or Medicaid certified? What are both the restrictions and advantages of the certification?
- How will the hospice staff, working with the family, honor the wishes of the person with dementia?
- What is the role of the primary care physician once hospice care begins?
- How many patients is each hospice staff member responsible for?
- What services do volunteers offer? What screening and type of training do volunteers receive?
- How quickly does the hospice staff respond to after-hour emergencies?
- How does the hospice work with the nursing home staff?
- How does the hospice ensure quality care?
- What expenses will require out-of-pocket pay?
- Is the family told what to expect in the dying process and what happens after the death?
- What services are available to help the family deal with grief and loss?
- Will the hospice benefit cover:
  - Equipment
  - Supplies
  - Medication
  - Ambulance
  - Hospitalization (short-term)
  - Nursing home respite
  - Pastoral consultation
  - Social worker
  - Nursing care
  - 24 hour access to a nurse

Are there other resources to help?

The Hospice Foundation of America – their mission “provides leadership in the development and application of hospice and its philosophy of care with the goal of enhancing the American health care system and the role of hospice within it.”
The National Hospice and Palliative Care Organization (NHPCO) explains hospice services, explores how to find a provider, gives resources to help, and more. The NHPCO Helpline (800) 658-8898 provides free consumer information on hospice care.
To reach the Missouri Hospice & Palliative Care Association or call 573.634.5514
To reach the Illinois Hospice & Palliative Care Organization or call 888.844.7706