What is Hospice Care

Hospice is a philosophy of care, which respects and values the dignity and worth of each person.

This philosophy is rooted in the commitment that no one needs to die in pain and that patients deserve to die with dignity. Dying with dignity incorporates pain control, the right to be heard, the right to be informed and the right to share in decision making. Therefore, patients participate in their care and retain as much control over their lives as possible throughout their dying process. Hospices care for people approaching death, but hospices cherish and emphasize life, by helping patients (and those who love and care for them) live each day to the fullest.

Hospice recognizes that for this philosophy to be successful, the family and those near to the patient also need to be honored, supported and heard. This requires a team approach and a multi-faceted model.

The hospice philosophy or viewpoint accepts death as the final stage of life. Hospice affirms life and neither hastens nor postpones death. Hospice care treats the person rather than the disease; it focuses on quality rather than length of life.

Hospice care can be given in the patient’s home, a hospital, nursing home, or private hospice facility. Most hospice care in the United States is given in the home, with family members or friends serving as the main hands-on caregivers. Because of this, a patient getting home hospice care must have a caregiver in the home with them 24 hours a day.

Hospice care is used when the patient can no longer be helped by curative treatment and is expected to live about 6 months or less. Hospice offers palliative care, which is treatment to help relieve disease-related symptoms, but not cure the disease; its main purpose is to improve quality of life. The patient, patient’s family, and patient’s doctor decide together when hospice care should begin.

One of the ongoing challenges with hospice is that it is often not started soon enough. Sometimes the doctor, patient, or family member will resist hospice because he or she thinks it means you’re “giving up”, or that there’s no hope. This is not true. If symptoms get better or the disease goes into remission, the patient can be taken out of the hospice program and go into active treatment. The patient can go back to hospice care later, if needed. But the hope that hospice brings is the hope of a quality life, making the best of each day during the last stages of advanced illness.
Hospice Care Services

Many features of hospice care set it apart from other types of health care.

Pain and Symptom Control

The goal of pain and symptom control is to help the patient be comfortable while remaining in control of and enjoying life. This means that discomfort, pain, and side effects are managed to make sure that the patient is as free of pain and symptoms as possible, yet still alert enough to participate in his/her life.

A Team of Professionals

In most cases, an interdisciplinary health care team manages hospice care. This means that many interacting disciplines work together. Doctors, nurses, social workers, counselors, home health aides, clergy, therapists, and trained volunteers care for the patient and his/her family. The interdisciplinary team offers a multifaceted care program that provides complete palliative care aimed at relieving symptoms, providing comfort and giving social, emotional, and spiritual support.

Hospice care providers are trained to speak about issues that family members often find the most difficult. They are trained to empathize with the dying person and listen compassionately to fears, worries, concerns and questions about dying. This support is one of hospice’s greatest blessings.

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THERE ARE FOUR GENERAL LEVELS OF HOSPICE CARE:

Home-based Care

1. Routine Home Care: Patient receives hospice care at the place he/she resides.

2. Continuous Home Care: Patient receives hospice care consisting predominantly of licensed
nursing care on a continuous basis at home. Continuous home care is only furnished during brief periods of crisis and only as necessary to maintain the terminally ill patient at home.

**Inpatient Care**

3. General Inpatient Care: Patient receives general inpatient care in an inpatient facility for pain control or acute or complex symptom management which cannot be managed in other settings.

4. Inpatient Respite Care: Patient receives care in an approved facility on a short-term basis in order to provide respite for the caregiver

**Respite Care**

While the patient is in hospice, the patient’s family and caregivers may need some time to themselves. Hospice service may offer them a break through respite care, which is often offered in up to 5-day periods. During this time the patient will be cared for either in the hospice facility or in beds that are set aside for this in nursing homes or hospitals. Families can plan a mini-vacation, go to special events, or simply get much-needed rest at home while the patient is cared for in an inpatient setting.

**Family Conferences**

Regularly scheduled family conferences, often led by the hospice nurse or social worker, keep family members informed about their loved one's condition and what to expect. Family conferences also give everyone a chance to share feelings, talk about what to expect and what is needed, and learn about death and the process of dying. Family members can find personal support and stress relief through family conferences.

**Bereavement Care**

Bereavement is the time of mourning after a loss. The hospice care team works with surviving loved ones to help them through the grieving process. A trained volunteer, clergy member, or professional counselor provides support to survivors through visits, phone calls, and/or letter contact, as well as through support groups. The hospice team can refer family members and care-giving friends to other medical or professional care if needed. Bereavement services are often provided for about a year after the patient's death.

**Volunteers**

The U.S. hospice movement was founded by volunteers and there is continued commitment to volunteer service. Volunteers may be health professionals or lay people who provide services that range from hands-on care to working in the hospice office. NHPCO estimates that in 2012, 400,000 hospice volunteers provided 19 million hours of service. Hospice volunteers provide service in three general areas:
• Spending time with patients and families (“direct support”) Hands-on care such as massage
• Providing clerical and other services that support patient care and clinical services (“clinical support”)
• Helping with fundraising efforts and/or the board of directors (“general support”).

Hospice is unique in that it is the only provider whose Medicare Conditions of Participation requires volunteers to provide at least 5% of total patient care hours. In 2012, 5.4% of all clinical staff hours were provided by volunteers.

Coordination of Care
The interdisciplinary team coordinates and supervises all care 7 days a week, 24 hours a day. This team is responsible for making sure that all involved services share information. This may include the inpatient facility, the home care agency, the doctor, and other community professionals, such as pharmacists, clergy, and funeral directors. The patient and the caregivers are encouraged to contact their hospice team if the patient is having a problem, any time of the day or night. There is always someone on call to help the patient with whatever may arise. Hospice care assures the patient and family that they are not alone, and help can be reached at any time.

SUMMARY
What Services Are Provided?
Among its major responsibilities, the interdisciplinary hospice team: *Manages the patient’s pain and symptoms
• Assists the patient with the emotional and psychosocial and spiritual aspects of dying
• Provides needed drugs, medical supplies, and equipment
• Coaches the family on how to care for the patient
• Delivers special services like speech, physical therapy, and massage when needed
• Makes short-term inpatient care available when pain or symptoms become too difficult to manage at home, or the caregiver needs respite time
• Provides bereavement care and counseling to surviving family and friends.

Sources
https://www.nhpco.org/about-hospice-and-palliative-care/hospice-faqs
Hospicelink 800.331.1620 • Telephone 207.255.8800
Telefax 207255.8008 • info@hospiceworld.org
A SHORT HISTORY OF HOSPICE

Special ways of caring for the dying have evolved around the world throughout history.

For example: in old China the “death houses” offered a place for the destitute dying to stay; in New Zealand, Maori customs gave practical support for the family at the time of death, and encouraged the community to participate in the mourning rituals; in East Africa, wise elders gave both practical and spiritual support to the dying and bereaved.

In western Europe and North America, until the 19th Century, caring for the dying and the bereaved was seen primarily as the job of the family and the church. In the last 100 years, dying has increasingly been seen as a medical event, not as a milestone in the life and history of a family.

In the Middle Ages religious orders establish “hospices” at key crossroads on the way to religious shrines. These shelters helped pilgrims, many of whom were traveling to these shrines seeking miraculous cure of chronic and fatal illnesses, and many of whom died while on their pilgrimages.

In the 16th-18th Centuries religious orders offered care to the sick (including the dying) in locally or regionally based institutions. Most people died at home, cared for by the women in the family. In the 1800’s Madame Gamier of Lyon, France opened a “calvaire” to care for the dying.

In 1879 Mother Mary Aikenhead of the Irish Sisters of Charity opened Our Lady’s Hospice in Dublin, caring only for the dying.

By the late 19th Century, the increase in municipal or charitably-financed infirmaries, almshouses and hospitals, and the expansion of medical knowledge, began and the process of “medicalizing” dying. (By the mid-20th Century, almost 80% of people in the U.S.A. died in hospitals or nursing homes.)

In 1905 the Irish Sisters of Charity opened St. Joseph’s Hospice in East London, to care for the sick and the dying. In the early 1900s, in London, St. Luke’s Hospice and the Hospice of God opened to serve the destitute dying.


From 1957-67: Cicely Saunders, a young physician previously trained as a nurse and a social worker, worked at St. Joseph’s Hospice, studying pain control in advanced cancer. Here Dr. Saunders pioneered in the regular use of opioid analgesics given “by the clock” instead of waiting for the pain to return before giving drugs. This is now standard practice in good hospice and palliative care.

In 1967 Dr. Saunders opened St. Christopher’s Hospice in London, emphasizing the multidisciplinary approach to caring for the dying, the regular use of opioids to control physical pain, and careful attention to social, spiritual and psychological suffering in patients and families.

From 1968-75 many hospice and palliative care programs opened in Great Britain in the years following, adapting the St. Christopher’s model offering in-patient and home care.
In 1974 New Haven Hospice (now Connecticut Hospice) begins hospice home care in the United States, caring for people with cancer, ALS and other fatal illnesses.

From 1974-78 hospices and palliative care units open across North America These include Hospice of Marin in California, the Palliative Care Unit at the Royal Victoria Hospital in Montreal, the Support Team at St. Luke’s Hospital in New York City, and Church Hospital Hospice in Baltimore.

Throughout the 1980’s, largely due to the need to care for those dying from aids, hospice care, usually emphasizing home care, expands throughout the United States.

Medicare adds a hospice benefit in 1984. Hospices begin to care for people with advanced AIDS.

From 1990-2000 over 3,000 hospices and palliative care programs formed in the United States. There was well-established hospice and palliative care in Canada, Australia, New Zealand, and much of Asia and Western Europe during this time.

Hospice and palliative care was made available in over 40 countries worldwide, including many less-developed nations. The World Health Organization set standards for palliative care and pain control, calling it a “priority.” But studies showed that most patients still received little or no effective palliative care, and pain was often very poorly controlled, primarily due to lack of medical knowledge, to unfounded fears of addiction, and (in less-developed nations) to shortage of opioids.

In the 21st Century the principles of good hospice and palliative care became understood and accepted, and all patients with advanced illness, and their families, are assured of competent and compassionate care in their homes, in nursing homes and in hospitals.

In the United States today, over 5,000 programs offer specialized care to people suffering from fatal illnesses. Good hospices are rooted in, and responsive to, the communities they serve, and to the people who live and die there.


Some Facts;
In 2012 an estimated 1.5 to 1.6 million persons were cared for by hospice.

The median (50th percentile) length of service in 2012 was 18.7 days, this means that half of hospice patients received care for less than three weeks and half received care for more than three weeks. The average length of service in 2012 was 71.8 days

In 2012, 66.0% of patients received care at home. this includes private residences, nursing homes and residential facilities. The percentage of hospice patients receiving care in a hospice inpatient facility was 27.4%

In addition to providing home hospice care, about one in five hospice agencies also operate a dedicated inpatient unit or facility Most of these facilities are either freestanding or located on a hospital campus and may provide a mix of general inpatient and residential care.

Short-term inpatient care can be made available when pain or symptoms become too difficult
to manage at home, or the caregiver needs respite.

Today, cancer diagnoses account for (36.9%) of hospice admissions. The top four non-cancer primary diagnoses for patients admitted to hospice in 2012 remained debility unspecified (14.2%), dementia (12.8%), heart disease 11.2%), and lung disease (8.2%).

The Medicare hospice benefit enacted by Congress in 1982, is the predominate source of payment for hospice care. The percentage of hospice patients covered by the Medicare hospice benefit versus other payment sources was 83.7% in 2012.

Source https://www.nhpco.org/about-hospice-and-palliative-care/hospice-faqs

### THE DYING EXPERIENCE

Michael was the first client that I worked with through his dying process. I was not prepared for the physical changes I witnessed in his body nor was I prepared for the personality changes that Michael went through as he became more reliant on pain medication and needed less from the social world. I experienced feelings that something was terribly wrong. The physical deterioration was scary to me. I blamed it on Michael's care. I went through a great deal of needless blame, anger and suffering because I didn’t understand the physical and emotional changes I was witnessing.

Barbara Karnes, R.N., long time hospice nurse, author, and international speaker, in her booklet Gone From My Sight, speaks to the physical signs that occur as one approaches death. These signs include:

- **Withdrawal from the world**
  
  This stage includes letting go of the more social aspects of the world such as television, then possibly the friends, then family. This stage includes sleeping more as well as communicating less verbally. Karnes speaks to this stage as a progressive need for personal reflection.

  This may be a time when the client pulls away from extra support such as massage. Even though touch allows and even provides for a personal reflective space, the client may feel that he/she must acknowledge the practitioner, and this requires energy. Don’t take it personally.

- **Letting go of food**
  
  With letting go of the world there is less of a need for food. Karnes suggests that there is a gradual decrease in eating habits, first letting go of heavy foods such as meat then soft foods. Then soft foods yield to liquids.

  It’s difficult for the care givers as well as the family to accept this gradual decrease in the desire for food. It’s hard to allow someone to stop eating. Everyone feels helpless. I have witnessed the agony of the family members many times as they watch their loved one push away the food and grow thin and weak.

- **Disorientation**

  As the dying person comes closer to death he/she may have the eyes closed most of the time. This may or may not indicate a deep sleep. Karnes says that during this period a client may be having conversations that you do not understand. He/she may be picking at the bedclothes or exhibiting agitated arm movements. In my experience the dying person seems to be in slow motion.
with all movements. It’s as if the person is in water.

The dying person seems to be processing his or her life experiences, having conversations that were unfinished, saying things they never got to say, or always wanted to say, and talking to loved ones that have died before. The client may be in the middle of a conversation that does not include me.

When my roommate died he would ask me to move over sometimes because I was in the way of someone he was talking to. He had many angels and talked to them constantly.

Dr. Elisabeth Kubler-Ross teaches that what sometimes appears to be a dying person’s verbal confusion, may be symbolic language.

A hospice client of mine, Michael, was very verbal and experiencing great struggle in his dying process. He was waving his arms and saying bottle, wheels, hallway, and room over repeatedly. It felt important to listen. Michael’s home was very important to him and he had not seen it for months. We, his care givers, believed he was saying, “Put away the bottle (which meant his sleeping medication), wheel me down the hallway, and let me see my house.” We did just that. Michael became peaceful and died the next day.

*Physical Changes:* Karnes says the following physical changes occur one to two weeks before death:

- blood pressure lowers
- pulse rate fluctuates from fast to slow
- skin color changes may include a yellowish pallor, and nail beds, feet and hands may be pale and bluish because blood circulation is slower
- breathing changes

Respiration may obviously increase or decrease. There may be a puffing or blowing on exhale and there may be times when the breath stops and then picks up again. I have witnessed what seemed like an eternity between breaths. There may also be a rattling sound as the throat and or lungs become congested. Coughing may accompany the congestion.

*Days or Hours Before Death*

The signs listed above intensify. The dying person may also experience a surge in energy. If someone has been unresponsive they may wake up and talk to the people at the bedside. He/she may ask for a favorite food. I’ve had clients suddenly awake a few days before they died and tell me how wonderful our sessions have been and thank me for being present. I experience clients with very bright and clear eyes during this surge and most often with a sense of joy and gratitude.

Eyes may settle half open, Karnes states, glassy and teary, pulse is weak, and there is a decreased output of urine. Breathing becomes more irregular and labored.

Finally, the labor is over. The breath stops. Karnes says there may be one or two long spaced breaths following what appears to be the last breath.
Sitting with clients after this last breath has been a great blessing for me. In all cases I had the opportunity to witness the changing of the physical body in ways that give me great hope in the essence of life. In all cases I witnessed the pain leave the face, the body relax, and felt and have seen energy rise from the physical body in the form of mist and return to the atmosphere. These have been extraordinary opportunities to experience death as a process of change.

Each person approaches death in his/her own way and death comes in its own time. I have rushed to the bedside to say good-bye to my clients only to have them rally and live way past the time expected. I have put off going to see clients until a next scheduled visit and they have died. Please keep this in mind as you integrate the timetable of physical signs listed above.

Reference: Gone From My Sight, author Barbara Karnes, R.N. www.barbarakarnes.com