"In June, Mother's doctor asked for a family decision about stomach tube feeding. Dysphasia, along with the dementia, was sabotaging her ability to swallow enough nourishment to sustain life. When I talked to Mother about the doctor's request, I was grateful that she had the clarity to let me know her choice. She shook her head in disapproval."

- Carol Ann Young, Author

- Adapted from Always on Call, Edited by Carol Levine
Depending upon your loved one’s diagnosis, there may be a number of different treatment options available, and each option may have both advantages and disadvantages. The patient has the right to make informed decisions about his/her medical care. This is what is referred to as “Informed Consent.” In order to make an informed decision you and the patient should know:

■ Specific information about the patient’s diagnosis and recommended treatment.
■ The goals of treatment (e.g. cure, symptom relief).
■ The risks and benefits of treatment.
■ What to expect after treatment (e.g. side effects, recovery time).
■ What to expect if treatment is refused.
■ The costs for each treatment option, including what is and is not covered by insurance.
■ If there are any alternatives to the recommended treatment.

The doctor should thoroughly discuss each of these topics with you and the patient and allow both of you to ask questions and voice any concerns. You and the patient should be sure that you understand all of the information before agreeing to or refusing treatment.
The person who is appointed may be referred to as the patient’s health care agent, surrogate, attorney-in-fact, or proxy. This individual can be a friend, family member, or partner. It should be someone who is familiar with the patient’s views about medical care, including the role of life-sustaining treatments like mechanical respiration, and will uphold his or her wishes as medical situations arise.

In order to designate a health care agent, a form must be filled out, which becomes a legally binding document. This form must be signed by the patient, health care agent, and a witness. After the proxy form is signed, hospitals, other health care facilities, and all health care professionals are legally obligated to follow medical instructions given by the health care agent, if the patient is unable to communicate. In the event that the patient’s first choice is unable to uphold the patient’s medical wishes, an alternate agent may also be chosen. Agents can be changed at any time if the individual decides that someone else would be better able to represent him or her.

Advance directives are statements made by the patient that describe the treatments that should or should not be given in the event a medical situation arises which requires a decision about therapy, and the patient is unable to speak for him or herself. For those living with serious, progressive illnesses, the future is unpredictable and these patients should decide on treatments while they are mentally capable of doing so. Patients can be sure that their wishes are followed by executing advance directives with the help of a lawyer. While laws vary in each state, most recognize at least one of two advance directives:

- Health Care Proxy
- A Living Will

**Health Care Proxy**

A Health Care Proxy, also referred to as a “Medical/Durable Power of Attorney for Health Care,” is a legal form that authorizes a person of the patient’s choice to make health care decisions for the patient if he/she is unable to do so.

Health Care Proxy forms can be obtained from the hospital or by contacting:
Choice in Dying/Partnership for Caring
1035 30th Street, NW
Washington, D.C. 20007
(800) 989-WILL (9455)
www.choices.org
www.partnershipforcaring.org
A Living Will is a set of written instructions that outline the patient’s health care wishes at the end of life. If the patient completes a Health Care Proxy form, but also has a Living Will, the Living Will provides the instructions for the proxy. It is important for everyone to have a copy of the patient’s Health Care Proxy, including his/her doctors and hospital, and that it is in the patient’s chart.

Advantages of Advance Directives:
▲ Help patients express their future wishes about medical treatment.
▲ Ensure that patients will not be given medical treatments they do not want.
▲ Take pressure off family members if decisions must be made about medical care and patients are unable to communicate.
▲ Patients can choose a person they feel will best represent their wishes and can make serious decisions about their health care.
▲ Patients can change living wills or health care proxies at any time.
Palliative Care focuses on the physical, psychosocial, and spiritual concerns of patients with life-threatening illnesses at any phase of their disease. This offers patients many options to ensure comfort and quality of life throughout the duration of their illness. For patients with incurable diseases who are undergoing active, life-prolonging therapies and have life expectancies that can extend to years, palliative care includes:

- Management of distressing symptoms, such as pain and fatigue.
- Restoration of function.
- Practical support for the patient and family.
- Psychological interventions.
- Concern for spiritual health.
- Clear discussions about the goals of care (with advance directives).

For dying patients, palliative care includes comfort for the patient and preparation of both the patient and family for the inevitability of dying. This preparation may address a broad range of psychological, social, family, and spiritual concerns.

At all stages of the disease, effective palliative care increases the likelihood that the patient will cope adequately with the rigors of therapy and maintain a satisfying level of physical and psychosocial functioning.

End-of-Life Care

Once it becomes clear that your loved one is unlikely to recover, you will be faced with a variety of concerns, difficult choices and decisions. Some of the biggest concerns for the patient revolve around fears related to suffering, loss of dignity, and causing family members distress. It is important to recognize that you and your loved one have options that can help make the end of life less stressful. Even though curing the disease may not be possible, doctors may recommend treatments that can control the disease or its complications, such as:

- Chemotherapy to continue to destroy cancer cells.
- Antibiotic therapy to help treat infections resulting from an underlying condition.
- Renal dialysis to take over function for the kidneys if they fail to work.
- Surgery to remove tumors or diseased organs.

When a patient’s condition deteriorates, doctors may recommend treatments that are life-sustaining, such as:

- Artificial ventilation to help the patient breathe.
- Tube feeding and hydration to give the patient nutrients that they are unable to take in by mouth.
- Cardiopulmonary resuscitation (CPR) to restore heart-beat and breathing if the patient stops doing so on his or her own.
In making these important decisions you and your loved one should become well-informed by speaking to the doctor, considering your own personal values, examining treatment alternatives, and understanding legal and ethical issues.

To help with this decision, consider these questions:

▲ What is the prognosis/outcome of your loved one’s illness?
▲ How much of an impact would continued treatment have on your lives?
▲ How much time would be gained from life-sustaining treatment?
▲ What are your feelings about relying on machines and tubes to stay alive?
▲ What is the level of discomfort the patient is willing to withstand to live longer?
▲ Would your loved one want to remain on life support even if he/she is not likely to regain consciousness?
▲ How important is staying alive to the patient as opposed to being able to live independently?
▲ Are there any alternative treatment options?

For seriously ill patients, treatments can prolong the dying process and lead to dependence on machines and tubes to live. Patients may experience more pain and discomfort and can remain unconscious for long periods of time with the use of such procedures and apparatus. These factors can make it difficult to spend quality time with the patient and can cause a great deal of suffering for both the patient and the family. Patients and caregivers should understand that all of these interventions can be refused. Patients can choose to have palliative/comfort care alone at any time. Many patients also opt to have a do-not-resuscitate (DNR) order, which tells health care providers not to use CPR if the patient’s heart and breathing stop (see DNR Fact Sheet). These choices can offer patients comfort, a more peaceful death, time to spend with loved ones, freedom from machines and tubes, and the possibility of dying at home.
Hospice care services

Home Care Visits
Hospice care is provided by an interdisciplinary team of professionals consisting of nurses, physicians, social workers, counselors, clergy, volunteers, home health aides, and special therapists. Team members make regular visits to the patient’s home and work together to plan and coordinate care, such as:

- Providing medical care.
- Instructing the family on how to manage the patient’s physical and emotional symptoms such as pain, anxiety, or confusion.
- Assisting with the personal care of the patient such as bathing and feeding.
- Helping with household chores.
- Offering emotional support to the patient and family.

Transportation
Ambulance service to and from an inpatient admission is provided as part of most hospice programs. Outpatient transportation is provided on an individual basis based on the medical necessity of ambulance/ambulette care and individual insurance carrier coverage.

Counseling
Emotional support is offered for both the patient and family through such means as counseling, music, prayer, or companionship. Depending on the needs of the patient and family, there are many avenues for support:

- Social workers with whom one can talk and sort through personal issues.
- Chaplains to offer spiritual counseling consistent with one’s faith and beliefs.
- Music therapists to address feelings and offer comfort through music.
- Volunteers to lend an ear and provide companionship.

What is hospice?
Hospice is generally not a specific place— it is a specialized program of care for patients with a limited life expectancy and for their family and friends. With its comprehensive array of medical and social services, hospice strives to meet each patient’s unique physical, emotional, social and spiritual needs, as well as the special needs of the patient’s family and close friends. The goals of hospice are to help the patient have as good a quality of life as possible, and to assist caregivers in their efforts to keep their loved ones in the comfort of their own homes. This includes keeping the patient as comfortable as possible by relieving pain and other uncomfortable symptoms, preparing for a death that follows the wishes and needs of the patient, and reassuring both the patient and family members by helping them understand and manage the patient’s care. This support assists patients and families through the process of facing, understanding and preparing for death.

“I have been telling anyone who’d listen that hospice nurses are angels. Hospice appeared in the life of my wife and myself when we’d become desperate as a result of her worsening cancer. Traditional medicine was no longer helping us. From the moment they walked through our door, the hospice staff offered us compassion, professional skill, and 24-hour attention at every level – from medical issues to volunteer services to equipment delivery. They brought to my wife, and all at her bedside, a kind of peace.”

- Husband of a hospice patient
Inpatient Care
Short-term inpatient care is available for problems that cannot be relieved or managed at home. Hospital admissions related to the primary illness take place at a contracted hospice bed in a hospital affiliated with the hospice program. Under most insurance plans, patients may also be admitted for “respite care” for a limited time period of up to 5 days. Respite care is offered so that the family can take a break from the rigors of caring for their loved one at home.

Bereavement Counseling
Coping with the loss of a loved one is not an easy task. After a loved one dies, there is usually a period of mourning, which is referred to as bereavement. The bereavement program serves to support caregivers/family members during this time in a manner that takes into account their individuality, personal styles, and particular belief systems. Bereavement services are offered for 12 months following the death of a loved one. Services may include:

- Short-term individual counseling
- Bereavement groups
- Telephone follow-up
- Educational and inspirational mailings
- Referrals for services in the local community

The Hospice Team and What They Do

Nurse
The hospice nurse will visit weekly or as necessary. The nurse will use this time to assess the patient’s health status, tend to any medical needs, determine needs for home health aide services, and instruct and counsel the family on caring for the patient. The nurse will communicate directly with the doctor about the patient’s health status and adjustments in medications, which may be necessary to maximize comfort.

Physician
Visits with a hospice physician can be scheduled for patient evaluation. Otherwise, the physician usually sees the patient as an outpatient, or, as an inpatient during hospital admissions.

Social Worker
The social worker will visit the home for an initial assessment to further understand how the illness is affecting the patient and family. The social worker will offer emotional support, counseling, and education about community resources to the family. He/she will visit weekly or as needed.

Home Health Aide
Under most insurance plans, hospice provides limited home health hours based on assessment of patient needs and evaluation of available resources. Home health aides are trained and certified to assist with personal care to the patient in the home. The home health aide works under the direction of the hospice nurse with a written plan of care. He/she will report any changes in the patient’s condition directly to the Nursing Supervisor and will keep records of the patient’s care as instructed by the nurse. Services provided by home health aides may include:

- Assistance with bathing, washing hair, shaving, mouth care, dressing changes, toileting, and other personal care.
- Preparing and serving prescribed diet and, if necessary, helping the patient with eating.
- Assistance with prescribed exercises.
- Performing household tasks essential to patient’s well-being, such as making and changing the bed, doing the patient’s laundry, tidying the patient’s room and bathroom, and grocery shopping.
- Escorting the patient to and from appointments, as needed.
**Chaplain**
Chaplains are available for the patient and/or family for counseling, prayer, and coordination with the family rabbi, priest, minister, or imam. They will assist within the framework of the beliefs and values of the patient and/or family.

**Volunteers**
Volunteers are able to help in many ways, such as staying with the patient while the caregiver goes out, helping with transportation, providing companionship, assisting with personal care of the patient (e.g. massage), and many other areas in which the patient or family need help.

**Music Therapist**
The music therapist may be available to work with the patient and/or family to promote relaxation, expression of feelings, and sharing of memories with others through music.

**General guidelines for caring for a hospice patient at home**
While caring for a terminally ill patient at home, it is important to use precautions to prevent blood and other body secretions from coming into contact with any cuts or open areas on the skin. Hand washing before giving direct care protects the patient who is susceptible to infection. Hand washing after care will protect you, the caregiver. The following precautions are recommended by the Centers for Disease Control and should be observed:

- Wash your hands thoroughly, especially prior to performing direct physical care and before eating.
- Use gloves to protect hands whenever there will be excessive amounts of bodily fluid contact or where breaks in the skin occur.
- Gloves are not necessary when handling patient clothing and other articles or when touching the patient’s intact skin.
- Keep hands away from your mouth and face while working with the patient.
- Disposable gowns should be worn when your clothing is likely to be in contact with secretions and excretions. Discard the gown after use in the regular trashcan.
- Use disposable needles and syringes and discard in a sharps container. If unavailable, use a rigid, puncture-resistant container, such as a bleach bottle or coffee can.
- Do not recap needles, and do not purposely bend or break by hand, since accidental needle puncture may occur.
- Dispose of waste, such as soiled tissues, dressings, bandages, and gloves in plastic bags that are closed and secured tightly.
- Wastes which cannot be flushed down the toilet should be placed in two plastic bags and thrown directly into regular trash pickups, not in a household trashcan. Be sure to use a plastic liner in the trashcan and a tight-fitting lid to keep out animals.

**What to do as death approaches**
This particular phase of caregiving is likely one of the most difficult life experiences that you will have. This is an extremely emotional and overwhelming time. You may find it helpful to identify additional individuals you can call for support. It also helps to be informed about what to expect at the end of life so that you can be prepared when the time comes. Although it is difficult to predict exactly when a terminally ill person will die, a combination of signs and symptoms can signal that the time is getting close. Not all symptoms will appear at the same time, and some may never appear. However, all of the following symptoms are normal and expected at the time of death. If you have any questions or concerns, do not hesitate to call your hospice office.
**Signs and symptoms of approaching death**

- Hands, arms, feet, and legs may become cool to touch. You may notice the underside of the body becoming much darker in color. The skin may turn a bluish color with purplish splotches. This is the result of blood circulation slowing down.

**What To Do:**
- Use blankets for warmth to prevent the feeling of being cold.
- Do not use an electric blanket or heating pad.
- Be aware that occasionally arms and legs may be cool to touch, but the patient may state that he/she is hot and kick off the blankets.

- Your loved one will gradually spend more time sleeping during the day and may be difficult to arouse at times. This is the result of a change in the body's metabolism.

**What To Do:**
- Plan time and activities with your family member for those occasions when he/she seems most alert.
- Don’t confuse withdrawal with rejection. Your loved one may not wish to carry on a conversation much of the time, but may be comforted by your voice talking or reading from a favorite book or verse.
- Soft quiet music may be comforting at this time.

- Decreases in the need for food and fluids may occur. Your loved one will probably say that he/she doesn’t have an appetite and isn’t hungry. The body naturally begins to conserve energy and requires less nourishment. This is the body’s natural response to the dying process. It is telling you that eating and drinking are no longer helpful and that the body can no longer use food and fluid properly.

**What To Do:**
- Contact the hospice nurse so he/she can suggest alternative ways to give medications.
- Offer fluids in small sips, but do not force.
- Allow your loved one to choose when and what to eat or drink, even if this means little or nothing will be eaten or drunk.
- Offer food and drink, but do not force.
- Nutritional supplements may be indicated in some cases but, again, do not force.
- Discuss alternatives with the hospice nurse.

- Your loved one will probably say that he/she doesn’t have an appetite and isn’t hungry. The body naturally begins to conserve energy and requires less nourishment. This is the body’s natural response to the dying process. It is telling you that eating and drinking are no longer helpful and that the body can no longer use food and fluid properly.
There may be a change in bowel or bladder habits. Loss of control of bowel and/or bladder may occur. If there is a bladder catheter (Foley) in place, you will notice the urine becoming dark, with the amount decreasing as death comes closer.

What To Do:
▲ Ask the hospice nurse for pads to put on the bed to protect the linen.
▲ Change pads as needed to keep the bed as clean and dry as possible.
▲ Ask the hospice nurse to show you how to place pads under the patient and other ways to keep the skin clean, warm, and dry.

Changes in breathing patterns may be noticed. Irregular breathing may occur and there may be a pause for 10-30 seconds where there is no breathing at all. This is called apnea. You may also notice that there are oral secretions that will collect in the back of the throat and cause a noisy breathing called a “death rattle.” This happens when a person is too weak to cough or swallow. This symptom is common and indicative of a decrease in circulation and a building up of waste products in the body.

What To Do:
▲ Remind the patient of the day and time, and who is there with him/her.
▲ Talk to the patient calmly and reassuringly.
▲ Sit next to the bed and hold the patient’s hand to provide comfort.
▲ React calmly and behave with confidence, so as not to startle the patient further.
▲ Always talk as if the patient can hear you, even if he/she appears to be unconscious.
▲ When providing care, explain what you are doing.
▲ Keep a light on in the room (soft lighting without shadows) to decrease some of the confusion.

The patient may become increasingly confused about what time it is, where he/she is, and the identity of close and familiar people. The patient may also become restless, see things that are not there, or pull at the bed linen. This is caused by decreases in oxygen circulation to the brain and changes in the body’s metabolism.
What To Do:
▲ Changing the patient’s position may help the breathing, but don’t become alarmed if it doesn’t. A change in breathing pattern is normal and expected.
▲ When oral secretions build up, elevating the head off the bed with pillows or obtaining a hospital bed will make breathing easier.
▲ Use a cool mist humidifier in the room.
▲ Use a moist washcloth to relieve a dry mouth.
▲ Chapstick or vaseline to the lips may provide comfort.
▲ Try turning the patient on his/her side to keep secretions from getting caught in the throat.
▲ Call the nurse for further advice if the patient becomes distressed with these symptoms.

What to do at the time of death
■ Call the Hospice. Be sure to keep all numbers for the hospice in an accessible location, so you can refer to them quickly (list these numbers on the Emergency Information Sheet in Chapter 2).
■ DO NOT CALL 911 OR THE PARAMEDICS.
■ If you are alone, call a friend or family member to be with you.
■ Note the time that your loved one stopped breathing.
■ Call the funeral home. They will send someone to the house to take the body directly to the funeral home. You may instruct the funeral home to contact the hospice.

Hospice services are provided by Medicaid, Medicare, and many private insurers. If you are unsure if your loved one qualifies for hospice, speak to his/her doctor. To determine if the patient’s insurance covers hospice, you can call the insurance company directly. If insurance does not cover hospice, ask the hospice staff about other sources of financial assistance that may be available. To find out more about hospice or to locate a hospice program in your area, see Appendix F.

What To Do:
▲ Maintain a peaceful, quiet atmosphere.
▲ Keep soft lights on in the room when vision decreases.
▲ Soft music may be comforting.
▲ Be calm and reassuring.
▲ Never assume that the patient cannot hear you when talking to others in the room. Hearing is the last of the five senses to be lost.

Hearing and vision ability may decrease slightly.