The Hospice Option

Hospice: A Way station for weary travellers

- Hospice is a philosophy that has become a reality.
- Hospice is appropriate for anyone with a life limiting condition, having an approximate life expectancy of 6 months or less, and having decided to forgo any (additional) life extending treatment.
- Hospice provides comprehensive holistic care for the terminally ill and their families.
- Hospice is provider at home, in residential care facilities, in hospitals and in specialized Hospice centers.
- The focus of care is to optimize quality of life.
  - Relief of distressing physical symptoms.
  - Training and information for both patients and their primary caregivers. Emotional and spiritual support.
- Bereavement services for the family.

What Hospice provides

- Regular scheduled visits by hospice team members
- 24 hour on-call nurses and social workers
- Medications related to comfort and to primary hospice diagnosis
- Durable medical equipment: hospital bed, wheelchair, walker, oxygen, bath stool, bed-side commode, lifting device
- Disposable medical supplies: gloves, under-pads, mouth swabs, dressing supplies, diapers, etc.
- Continuous care: temporary ongoing care to support patient and family through a crisis situation
- Respite care: five day placement in skilled nursing facility to provide family with respite
- Additional services: Assisting patients and family to access end-of-life related legal services as well as other types of community support.
Your Hospice Team:

- Hospice Physician: provides back-up for primary care physician and consultation for hospice team
- Registered Nurses and Licensed Vocational Nurses: provides skilled nursing visits. Usually the registered nurse function as a patient’s care team coordinator
- Certified Nurse's Aides: provides personal care assistance
- Social Workers: emotional support, liaison to community services
- Hospice Chaplains: spiritual care
- Bereavement Coordinator: provides follow up support after a death
- Volunteer Coordinator: trains and assigns direct care volunteers as well as other types of volunteers
- Direct care volunteers: provide patient and caregiver support, respite
- Physical Therapy: safety needs for patient and caregivers
- Occupational Therapy: safety and energy conservation
- Speech Therapy: assistance with speech and swallowing issues
- Office Staff: the voice at the other end of the phone

Frequently Asked Questions

Who is eligible to receive Hospice care?
- You must have a diagnosis that is considered terminal
- Your prognosis or life expectancy should be six months or less according to your physician's estimation
- You should no longer be seeking curative or life-extending treatment

Who pays for all this?
- Medicare, Medicaid, private insurance, and private pay
- United Way and other grants and donations.
- Non-profit hospices are required to provide care for persons who have no source of reimbursement. For-profit hospices may limit the care provided to non-paying patients

Who will take care of me?
- You and your family are responsible for your daily care
- Residential care facility staff or hired caregivers
- Your hospice team members will visit you but will not provide around-the-clock care.
Will I keep my own doctor?
- Your hospice team will work closely with your own physicians.
- Some PCPs (Primary Care Physician) defer to the hospice physician for symptoms management.
- The hospice physician can become PCP for people who do not have a physician in the area.

How do I get signed up?
- Hospice has to be ordered by a physician.
- Talk to your physician. If your PCP agrees that hospice would be a good option for you, he or she will call hospice.
- Call your local hospice for an in-home evaluation. If hospice is an appropriate option for your family, your physician will be contacted for approval and orders prior to admission.
- There are many hospices; you should always be given a choice of which one to choose.

Do I have to go to a Hospice Home?
- Only if that is your choice.
- The majority of hospice patients are cared for at their primary residence.
- If you live alone, you will need to make arrangements for your care when you are no longer able to care for yourself.

What if I change my mind?
- Some people decide to take more treatment.
- You will not lose your eligibility for later service.

What if I live more than six months?
- The six months prognosis is merely a guideline.
- If your condition progresses as expected, hospice can continue as long as you need it.
- If your condition stabilizes, you will be discharged from hospice care until your health condition warrants re-admission.
How do you know when it is time to call hospice?

- If hospice even crosses your mind it is very likely time make that call.
- Has your physician suggested hospice or told you your treatment is no longer working and there is nothing more that can be done?
- Is the patient tired of doctors and hospitals?
- Has there been poor appetite and a significant weight?
- Has there been a loss of self-care ability?
- Has there been a change in strength and mobility?
- Has there been a change in level of consciousness, more sleeping, increased confusion

Hospice Myths

#1: Hospice is only for the last few days of life  
Fact: Hospice is for the last six months of life, or longer

#2: Hospice means you are giving up  
Fact: Hospice means you choose to optimize the quality of your life,

#3: Hospice means you will die sooner  
Fact: Nothing hospice does will shorten your time

#4: Hospice will stop all medications  
Fact: Hospice will manage medications, adding and subtracting

#5: Hospice will withhold food  
Fact: Hospice supports feeding as long as the patient benefits

#6: Hospice is only for cancer patients  
Fact: Hospice is for any terminal condition, including old age

#7: Hospice is only there for the patient  
Fact: Hospice provides care and support for the entire family

#8: Hospice is a place  
Fact: Hospice is a philosophy. Hospice is where you live
You have nothing to lose by calling hospice

- If it is not time yet, your hospice representative or your physician will tell you so
- If you sign up with hospice and change your mind, you can simply discontinue the service. The decision is always yours!
- If you are receiving hospice care and get better, hospice will cheerfully go away.
- Hospice does not change what is happening; it simply changes the conversation!
- You have nothing to lose but the pretense

Two major goals of hospice care:

Energy conservation:
- Management of pain and other distressing symptoms
- Environmental support: equipment needed
- Social adaptation: “crowd control”

Reducing anxiety:
- Hospice is there; you no longer have to do this alone!
- Information; knowing what to expect
- Learning the skills required to manage at home
- Mental, emotional, and spiritual support
- Getting your affairs in order/documents

Understanding and anticipating expected changes.

Sources of caregiver anxiety

Nutrition issues/myths:
- Diminishing energy and food
- Food is love
- You have to eat to keep up your strength
- Starving to death
- Feeding tubes
Hydration
- Diminishing energy and fluids
- Gravity and excess fluids
- Dehydration is a friend
- IV or tube hydration

Changes in level of consciousness:
- Diminishing energy and consciousness
- Increased need to rest
- Increased sleeping and medication
- “zoning out”
- “Hearing is the last to go”
- Asking for response

The right to make decisions for yourself includes the right to make bad ones

Books you might find helpful:
- Doughty, Caitlin. “Smoke Gets in Your Eyes: And Other Lessons from the Crematory”
- Kaee, Kirsten. “It Is about Time: Straight Talk about Aging and End of Life”
- Shaw, Eva. “What to Do When a Loved One Dies: A Practical and Compassionate Guide to Dealing with Death on Life’s Terms”
- Viorst Judith. “Necessary Losses”
- Weil, Andrew. “8 Weeks to Optimum Health”