

Hospice Care: Practical Information and Personal Reflections

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HOSPICE CARE: PRACTICAL INFORMATION AND PERSONAL REFLECTIONS

While a cancer diagnosis is no longer tantamount to a sentence of death, in my Mother's case, it was. In August of 2004 a five-inch malignant tumor was discovered in the liver of my otherwise healthy, vibrant and active 74-year-old Mom. The diagnosis was inoperable and untreatable liver cancer; therefore I had no choice but to ultimately accept the fact that she had approximately six months to live. In the fall of 2004, I attended a seminar offered by a local hospice designed to educate those professionals who provide services to the elderly on the fundamentals of the hospice program. While the information presented has proved to be helpful to me in counseling elder law clients, the main benefit that I derived was personal. I learned how this organization could assist my only surviving parent as well as family and friends in coping with the dying process on all levels.

This article addresses the following topics: history and structure of hospice, payment for services, services covered by Medicare. As suggested by the title of this article, one of the purposes in writing this piece is to share my individual perspective as a daughter and long distance caregiver. I therefore conclude the article with my own personal reflections.

The linguistic root of the word "hospice" is the Latin word "hospes" which refers either to a visitor or host who receives the visitor. The word "hospital", "hospitality" and "hostel" share the same origin. Dame Cicely Saunders, an English physician, started into motion the chain of events that would evolve into the modern version of hospice care. The hospice concept was first introduced to the medical community in the United States in 1965

by Dame Saunders who subsequently founded St. Christopher's Hospice in London in 1967. She lived out her final days in that facility where she passed away at age 87 on July 14, 2005.

Over the last half of a century, the hospice concept has evolved into a philosophy of care as opposed to a physical location. The current emphasis is on assisting patients to remain at home during their final days with medical professionals and volunteers offering in-home expert support to family and friends in caring for the dying person. Inpatient hospice units are available for those whose medical conditions cannot be safely or adequately addressed outside of an institutional context.

According to a 2003 report issued by the National Hospice and Palliative Care Organization (NHPCO), there were approximately 3,300 operational hospice programs in the United States serving an estimated 950,000 patients during that year. Half of those patients died at home. Cancer is the most common primary diagnosis for hospice patients, accounting for 49% of hospice admissions. The top five primary non-cancer diagnoses included end-stage heart disease, dementia, lung disease, end-stage kidney disease and end-stage liver disease.

Hospice's fundamental mission is to assist terminally ill individuals in living out their remaining days with dignity. The program is structured to provide palliative rather than curative treatment. Thus, the emphasis is on managing pain, enhancing comfort and quality of life as well as providing spiritual and emotional support to the patient and the family.

The tricky issue is when to seek hospice intervention. A requirement for enrollment is a medical diagnosis of a terminal illness which is generally measured by a prognosis of a life expectancy of six months or less. Statistics show that most do not take advantage of the

program until death is imminent. According to a 2000 survey taken by the Centers for Disease Control and Prevention, over two-thirds of hospice patients received fewer than 30 days of care with one-third receiving a week or less of care. The median length of service in that same year was 16 days.

The failure of so many to take advantage of the hospice benefit at an early date may be attributed to lack of education as well as reluctance to admit that someone is facing the end of their life. The prevailing attitude seems to be that life is over once hospice comes in. In addition, some individuals suffering from a serious illness choose to exhaust every available curative treatment no matter the agony that it may cause or the odds of success of the treatment, thus precluding the availability of hospice.

One of the most distinctive elements of hospice care is its focus on the family and other loved ones of the sick person. Assistance in the form of bereavement services is available after the patient's death. In fact, regulations require completion of a bereavement assessment in order to determine whether family members are at serious physical or mental health risk after experiencing loss.

PAYMENT FOR SERVICES

Fortunately, most have no need to be concerned about how hospice care will be financed. Most private health insurers, health maintenance organizations (HMOs) and other managed care plans as well as the Department of Veterans Affairs provide coverage for hospice care. (The State of New Jersey requires all insurance companies and HMOs operating within the State to provide a hospice benefit.) If a patient has limited financial

resources and no insurance or is ineligible for governmental benefits, many hospices provide services without charge.

Federal legislation was passed in 1986 permitting states to develop Medicaid coverage for hospice programs. Such benefits are available in most states, including New Jersey and Pennsylvania. Surprisingly, hospice services in New Jersey for those qualifying under the Medically Needy program are limited to pregnant women.

Until 1982, Medicare did not cover hospice services. Under legislation enacted in 1986, Congress established the permanency of the coverage. Finally, hospice was included as a nationally guaranteed benefit under President Clinton's 1993 health care reform proposal.

Those seeking Medicare hospice benefits must satisfy the following criteria: (1) The patient must be eligible for Medicare Part A. To qualify for Part A an individual must fall within one of the following categories: age 65 or over, qualified for Social Security disability benefits for at least two years, suffer from amyotrophic lateral sclerosis (ALS), have had a kidney transplant, or need regular dialysis; (2) the patient's physician and the hospice medical director must certify that the individual has less than six months to live if the disease runs its normal course. However, it should be noted that the hospice benefit consists of two 90-day certification periods and an unlimited number of subsequent 60-day periods. While the first 90-day certification must be issued by both the attending physician and the hospice medical director, all recertifications may be issued by either of them; (3) The patient (or legal representative) signs a statement choosing hospice care instead of other Medicare covered benefits to treat the terminal illness. However, Medicare will continue to pay for covered benefits for health issues not related to the terminal illness. The patient will be responsible

for any co-pays or deductibles; and (4) The care is received from a Medicare approved hospice program. According to the NHPCO, approximately 95% of hospices are Medicare certified.

Services Covered By Medicare

The Medicare hospice benefit is provided under Medicare Part A (Hospital Insurance). In recognition of the diverse intensities of care required by hospice patients, four levels of care are offered: Routine Home Care, Continuous Home Care, Inpatient Respite Care, and General Inpatient Care. The classification determines the rate of reimbursement from Medicare. Not surprisingly, 96% of hospice care falls into the Routine Home Care category.

The following services are covered: doctor services, nursing care, medical equipment and supplies, drugs for symptom control and pain relief, home health aide or homemaker services, physical, occupational and speech therapy, short-term care in a hospital, short-term respite care, social worker services, dietary counseling, bereavement counseling. Under The Medicare Act of 2003, a terminally ill patient who has not yet elected the hospice benefit is entitled to a consultation visit with the hospice medical director or other physician who is an employee of a hospice program. The 2003 legislation also provides Medicare payments for the services of a nurse practitioner.

There may be a co-pay of up to five dollars for prescription drugs or other products used for pain relief and symptom control. The drugs must be obtained from a hospice approved pharmacy. The patient is also responsible for a co-pay of five percent of the Medicare payment amount for inpatient respite care.

The following services are not covered: Treatment to cure the terminal illness; charges for room and board for hospice care in home, a hospice facility nursing home or other long term care facility such as assisted living; any care, medications, equipment or transportation that is not authorized by hospice.

The services offered include providing educational material and classes to the survivors about the normal grieving process, ability to participate in support groups, periodic visits by a bereavement volunteer and referral to a mental health professional where appropriate. Many who have benefitted from the services ultimately choose to participate in the hospice volunteer program. Volunteers are able to offer an extraordinary depth of comfort and support as a result of the compassion and empathy that is developed through the experience of their own personal losses.

Federal law requires a hospice provider to maintain written policies and procedures regarding advance directives as set forth in Section 1866 (f) of the Social Security Act. The patients must be informed of their rights to refuse or consent to treatments, and how to legally execute an advance directive. However, the provider may not require execution of an advance directive as a condition of providing care and may not discriminate against an individual who refuses to sign the document. Likewise, a signed DNR order is not a prerequisite to acceptance to the hospice program.

PERSONAL REFLECTIONS

After my Mother's cancer diagnosis, my family explored all treatment options and early on, she submitted to a mild form of chemotherapy which landed her in the hospital. She

decided (after a great deal of soul searching and prayer) to forego curative treatment and let nature take its course. She wanted to live her remaining days to the fullest extent possible. The pain and nausea that she experienced during the initial five months after her diagnosis were by and large controlled through relatively low doses of the appropriate medication. I happily flew out to my hometown where she still lived eight to ten days each month. We shopped, we ate, attended religious services, visited with friends and family and had a lot of fun. However, at the beginning of the sixth month, both the pain and nausea began to escalate. Like many cancer patients, she refused to take the morphine until she was actually in pain. The reason that pain is often undertreated is the unsubstantiated fear of addiction or side effects. Indeed, my mom wanted to retain her lucidity and also felt that taking regular doses of morphine was an admission that the disease was getting the best of her.

Based on my understanding that one of hospice's major roles is pain management, I began to investigate the program. I knew that my mom was eligible since she met the life expectancy requirement, was no longer seeking a cure, her physician agreed that hospice was appropriate and she was living in a secure environment with my stepfather acting as primary caregiver with the assistance of friends, church members and me. The myriad of available services convinced me that the program was right for our family. Since there was only one hospice in her town, the choice was easy. For those who live in communities that support multiple hospices, it may be wise to conduct phone interviews to help in determining which program is right for the family. Suggested questions are provided below.

Observations to Make and Questions to Ask When Evaluating a Hospice Program

- 1.** Clarify the admission policies of the hospice
- 2.** How did the telephone staff respond to the first call? Did you sense an attitude of competence, caring and patience?
- 3.** What services are provided and how soon can they begin?
- 4.** What support is available to the primary caregiver and the family? If a patient lives alone, can the hospice suggest alternatives?
- 5.** What are the respective roles of the attending physician, nurses and other health professionals?
- 6.** Who provides nursing on-call coverage for the hospice? How are after-hours emergencies or needs handled?
- 7.** How often will the nurse and social worker come to the home for routine visits? How often will a personal care aide visit the home?
- 8.** What is a hospice volunteer and what do they do?
- 9.** What steps will be taken to keep the patient comfortable? How will pain and other symptoms be managed?
- 10.** Does the hospice have its own inpatient unit?
- 11.** Is inpatient hospice care available for a patient who needs hospital care? Which hospitals have a contract with the hospice?
- 12.** Do local nursing homes have contractual arrangements with the hospice?
- 13.** How does the hospice handle the payment and billing? Who pays for the cost of hospice services?
- 14.** Are bereavement services available?

I gingerly broached the topic with my mom, emphasizing that bringing in hospice did not mean that death was immediately imminent. Prognosis of life expectancy is simply a physician's "best guess" based upon past experience with other patients suffering from similar diseases. In fact, some individuals have relied on hospice for as long as one to two years. Besides, if a patient elects to be discharged from hospice care, he or she can be readmitted at a later date.

Since my mother agreed to participate in an initial interview, the hospice social worker visited the next day and explained the program to her. I had already informed the

admissions coordinator that while my mom knew her condition was terminal, she did not wish to know her life expectancy. At the initial meeting, a description was given of the hospice team and their respective roles. (See below for description of Hospice Team) My Mom agreed to give the program a try, knowing that she could withdraw at any time. She signed the consent form and the hospice team shifted into high gear. The nurse conducted a comprehensive interview, as well as a physical examination. A Plan of Care was developed in conjunction with her oncologist.

The Hospice Team

Physician - Contributes to and approves the hospice's written plan of care and any modification. Normally, the patient's personal physician is involved. Otherwise, physician care is provided by the hospice.

Registered Nurse - Responsible for visiting the home of the patient regularly, conducting skilled assessments and reporting the patient's condition to the physician. Provides skilled pain management services and coordinates medical equipment, supplies and medication. Provides emergency on-call coverage day and night. Caregiver education is emphasized to enable the family in performing basic care functions.

Home Health Aide - Provides personal care assistance such as bathing and grooming under the supervision of the nurse.

Social Worker - Identifies psychosocial needs of the family and helps to identify community resources and other support systems. May offer guidance in insurance and governmental benefits issues.

Counseling Services and Spiritual Care - Offer emotional and spiritual support. May include clergy.

Trained Volunteer - Offers practical assistance to family, providing respite care for the caregiver and running light errands. Provide support, companionship and encouragement.

Other Therapists - Physical, occupational, respiratory and speech therapy where medically appropriate.

For the next two months, a registered nurse visited the home twice a week. The nausea and pain were by and large kept in check as a direct result of the hospice's advice regarding the appropriate administration of medication. Since I lived half way across the

country, I was grateful that one of the nurses gave me her personal cell phone number so that I could both convey and receive information regarding my Mom's condition. I had peace of mind that she was being closely monitored. My folks were informed of the availability of volunteers to come into the home to enable my stepfather to get out of the house on his own. Because my family had so many friends, neighbors and "church ladies", the volunteer was not called upon at that time. It should be noted that hospice patients are not required to be homebound. In fact, my mother remained active even after hospice intervened. She still attended church, went shopping and out to lunch.

When my Mom's health began to rapidly decline, I saw first hand the benefits of the relationships that had been established. During the final weeks of her life, the role of hospice took on greater intensity. At one point, the hospice nurse told me that while she could not predict with certainty how long my mom would live, she thought that death would come within the next two weeks. The nurse taught me what to do to make my mom more comfortable, and compassionately explained what to expect. She provided me with a short booklet entitled "Gone From My Sight - The Dying Experience" which outlined the physical and spiritual aspect of dying. A nurse's aide came every day to assist us. My mom stopped eating, started detaching and ultimately faded into an unconscious state. Knowing that someone was available twenty-four hours a day to answer questions and to come to the house if necessary was comforting.

My mom passed away peacefully at home on April 25, 2005 at 3:00 a.m. I was awake at the time and immediately called the hospice nurse. She arrived within 30 minutes of the call and contacted the funeral director. The fact that she had known my mom was a comfort.

While we waited for the funeral director, we prayed, we laughed and we cried. Her presence made all of the difference to me. I was deeply touched when the hospice nurses, aides, and the social worker came to the viewing to pay their final respects. I suspect that they, too, were grieving the loss of my mother and saying their good-byes to us helped them to move on.

While the social worker called us the following week and sent us information regarding bereavement care, we already had strong support systems intact and declined the offer. However, many do take advantage of these services. According to a 2003 survey conducted by the National Hospice and Palliative Care Organization (NHPCO), bereavement support is given to an average of two family members per death. In most cases, the service is not ongoing with an average of two to three contacts per person. Some hospice agencies offer bereavement care to families in the community who were not served by them prior to the death of a loved one. The NHPCO survey showed that 21% of those receiving bereavement care fell within the category of non-hospice bereaved persons.

By outlining my family's positive experience with hospice, I hope to encourage professionals to recommend early hospice intervention to their clients and to educate the public in this regard as well. As an advocate for the elderly, I want to raise awareness so that more will take advantage of hospice in order to enhance quality of life for the terminally ill. I am grateful that I will never make the statement made by so many: "I wish that I would have called sooner".