

UNDERSTANDING END OF LIFE ISSUES

“In this world nothing can be said to be certain, except death and taxes.” Benjamin Franklin coined this famous phrase over 250 years ago. And yet few people think about their end of life issues until it is inevitable. This lack of information and planning is unfortunate because there are many options for end of life care that can relieve suffering and decrease the burden on terminally ill people and their families.

Many people believe that the end of life will involve suffering physical pain, fear, and lack of support. Fortunately, advance planning can enable individuals and families to make plans for the end of their lives that ensures their physical, psychological, and care needs are fully met. The final phase of life can be a painless, fulfilling and meaningful time for dying people and their loved ones.

LEGAL OPTIONS FOR END OF LIFE CARE

Because people had a lack of control of health care decisions in the past, states have passed legislation that allows people to make decisions about their health care, including end of life care, and to name an individual or individuals who can make decisions should the person be unable to speak for him or herself. These legal options include a durable power of attorney for health care and a living will.

Durable Power of Attorney for Health Care

A Durable Power of Attorney for Health Care (DPAHC) is a legal document that must be completed by the person while s/he is of sound mind. Each state will have a specific format that must be used, and most require the document to be notarized or signed by two witnesses. A DPAHC is a document that gives the proxy or agent considerable authority to make decisions regarding housing, care, and

end of life decisions. Thus, people completing a DPAHC should carefully consider who they name as their proxies or agents in the document. If a change in family relationship occurs such as death or divorce, this document should be reviewed and changed as needed.

Living Will

A living will is a document that describes the care a person wishes to receive if diagnosed with a terminal condition. There are differences from state to state regarding when a living will becomes effective and the degree of authority the living will carries with health care providers. If states provide a specific format, it is wise to use that format to define one's wishes and to sign the living will form as specified by the state. Some states do not provide a specific form, and people can choose to write their own statement or to use forms provided by health care systems, online legal form providers, or other formats such as Five Wishes. Most living wills provide for naming a health care agent or proxy to advocate on behalf of the signer if the signer becomes unable to speak for him or herself. Most often the agent(s) or proxy named in the living will, will be the same person named in the HCDPA. Again, changes in relationships that may affect the agent or proxy should be revisited.

Completing a living will effectively requires some degree of medical knowledge to understand and plan for some of the common and less common events that typically occur at the end of life. Health care providers can provide guidance about many of these possibilities. Some attorneys have developed sufficient knowledge to provide guidance. Geriatric nurse care managers are unbiased health care professionals who are equipped to assist people in understanding the medical issues so that people will be

able to complete their health care directives with a full understanding of the possible issues that may occur near the end of life.

Completed HCDPA and living will documents should be copied and distributed to appropriate parties. The proxy or agent(s) should receive the original copies of these documents. Most of the time the same individuals will be named in both documents, but in any case the proxy or agent(s) should each receive an original document. Copies of the documents should be provided to the person's physicians, hospital medical record department, attorney, and any family members or friends as appropriate.

CARE OPTIONS FOR END OF LIFE

The most commonly feared end of life issues are physical pain, dealing with family relationships, and fear of the unknown. However, the end of life can be a time of physical comfort, peace, and meaning when plans are made in advance and expert assistance is sought in controlling physical symptoms, mending any broken relationships, and nurturing spiritual readiness for the next stage of being.

Great advancements have been made in reducing or eliminating physical pain and suffering as well as emotional stress through programs called palliative care and hospice care. Hospice care is broadly defined through Medicare guidelines as a program to reduce the physical and psychological burden for people in the last six months of life as determined by a physician, and who have ceased curative disease treatment. Palliative care is not the same as hospice care as it may be provided at any time during a person's illness, even from the time of diagnosis. And, it may be given at the same time as curative treatment.

These services are closely related as hospice care always provides palliative care. However, hospice care is focused on terminally ill patients—people who no longer seek treatments to cure them and who are expected to live for about six months or less.

Palliative Care

The Institute of Medicine defines palliative care in this fashion:

“Palliative care seeks to prevent, relieve, reduce or soothe the symptoms of the disease or disorder without effecting a cure.....Palliative care in this broad sense is not restricted to those who are dying or those enrolled in hospice programs....It attends closely to the emotional, spiritual, and practical needs and goals of patients and those close to them.” In other words, people do not need to meet the strict guidelines of Medicare hospice programs to participate in palliative care programs.

Palliative care is often provided for people who are suffering with long term, serious medical conditions who are still undergoing treatment and who may or may not ultimately die of their disease. Specifically, the objectives of palliate care include relieving symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite and difficulty sleeping. Improvement in physical symptoms enables people to carry on with their daily life and enhances their ability to tolerate medical treatments. Advocacy provided through palliative care helps people better understand their choices for care. Usually a team of professionals works along side the patient and family to reduce physical suffering, maximize healing, promote emotional well being, and to support the family and significant others who are impacted the individual’s illness.

Hospice Care

The American hospice movement began in the early 1970s. Hospice is defined as a philosophy of care. The hospice philosophy recognizes death as the final stage of life and seeks to enable patients to continue an alert, pain-free life and to manage other symptoms so that their last days may be spent with dignity and quality, surrounded by their loved ones. Hospice affirms life and does not hasten or postpone death. Hospice care treats the person rather than the disease; it highlights quality rather than

length of life. It provides family–centered care involving the patient and family in making decisions. (*The American Cancer Society, 2007*).

Hospice care is care provided by health professionals and volunteers at the end of life. The health care team offers medical, psychological and spiritual support to people nearing the end of their lives. The major goal of hospice care is to help people who are dying have peace, comfort and dignity during the last days of their lives. Hospice caregivers try to control pain and other symptoms so people can remain as alert and comfortable as possible. Hospice programs also provide services to support a patient’s family and provide bereavement services for a period of time after a person’s death.

Usually, a hospice patient is expected to live 6 months or less. Hospice care can take place at home, in a residential hospice, a nursing care facility, or a hospital. Hospice providers are usually Medicare-certified home health care agencies who provide a variety of services to people whose doctors determine have six months or less to live and for whom further curative treatment is futile. Medicare covers defined benefits, but Medicare and other hospice programs do not provide 24-hour nursing care services. Many families with people dying at home engage other home care agencies to assist in providing care as patients become more dependent on others to meet their needs.

The benefits provided by Medicare hospice programs include:

- Doctor services
- Nursing care—intermittent care and not 24 hour care
- Medical equipment (such as wheelchairs or hospital beds)
- Medical supplies (such as bandages and catheters)
- Medications for symptom control and pain relief
- Short-term care in the hospital, including respite care
- Home health aide & homemaker services—intermittent and not 24 hour
- Physical and occupational therapy as needed for comfort
- Speech therapy
- Social worker services
- Dietary counseling
- Pastoral counseling to help you and your family with grief and loss

According to the American Hospice Foundation, hospice is often not started in time to be of the greatest benefit to individuals and families. “While hospice care is most effective over a period of months, the median length of service in 2012 was 18.7 days and 35.5% of those served by hospice died within 7 days. (National Hospice and Palliative Care Organization: http://www.nhpco.org/sites/default/files/public/Statistics_Research/2013_Facts_Figures.pdf)

During the last weeks or days, there may be a time to control a patient’s pain and stabilize symptoms, but there is little time or strength to address spiritual and emotional needs. On the other hand, early referral to hospice allows time to say goodbye and reduces the chance that the family’s grief will be prolonged and complicated. Most hospice care is provided in people’s homes where a primary caregiver is necessary to ensure the hospice patient is safe and receives all appropriate care” (*American Hospice Foundation [AHF] 2004*).

The foundation goes on to say “Professional geriatric care managers are better positioned to discuss hospice well before the brink of death and to make it a comfortable part of the client education. Clients can benefit from information about hospice even if they do not face a life-threatening illness. Before the stress of a medical crisis, early discussions about hospice can facilitate open communication, avoid late referrals, and provide clients a choice and sense of control” (*AHF, 2004*).

MATRIX CASE HISTORY

Mr. J was a 94-year-old man who lived in an Assisted Living apartment in the Twin Cities metro area. He received the assistance of a Geriatric Care Manager to coordinate his medical appointments, to be the primary contact person of his health care team and to be the communication facilitator between his family and friends. Mr. J had numerous long-term health issues including a history of multiple surgical procedures and several chronic ailments. In addition, he often had to deal with complications of those conditions along with potential and often problematic side effects to his many medications. Mr. J was able to maintain independence in caring for his own personal needs.

Mr. J's Geriatric Care Manager spoke with him over the course of the time she worked with him and assured that he had Advance Directives in place and that his wishes in those directives were current and known to his family and named health care agents. After a recent hospitalization for complications related to one of his conditions he was connected with a palliative care clinic to help minimize the need for frequent hospitalizations as well as provide optimal symptom control while at home. Over the course of 10 months this plan worked well for Mr. J and any needed changes and updates to his care were easily accomplished with the palliative

team working in conjunction with his Care Manager and the nurse at his assisted living residence.

Early in the summer, Mr. J's general condition began to deteriorate and he demonstrated a decreasing appetite, decreasing strength and increasing fatigue. A check of his overall health found no causes for these changes. Mr. J began to verbalize that he had lived a good life and knew his time was growing shorter. His Care Manager began discussing the options he had for end-of-life care. Mr. J indicated that he wanted to remain free of pain and suffering and that he wished he could remain in his current apartment. When his Care Manager discussed hospice he became concerned as his only prior experience with someone receiving hospice care was his friend years ago, who went to a residential hospice. As such, Mr. J was resistant to discussing hospice until his Care Manager explained that 'hospice' care can take place anywhere the person wishes so long as they have needed assistance for personal care when the time comes. Mr. J asked the Care Manager to discuss this with his family. After this was done, a Medicare Certified Hospice agency was called to initiate services. Mr. J met with the hospice RN and social worker for the intake meeting which also included his family, his Care Manager and the nurse at his

residence. After this Mr. J had a primary hospice nurse and care team available to him for his health care needs.

Within weeks Mr. J's general condition continued to decline and Mr. J asked for more assistance with daily care needs including dressing, grooming and bathing. These services were provided by the Home Care Agency skilled in end-of-life care. Through the Medicare Hospice agency, Mr. J was able to have a bedside commode, hospital bed and oxygen delivered promptly and paid for by Medicare. This medical equipment helped to make him more comfortable, and allowed those caring for him to have the needed equipment. As he declined further, his Care Manager and the Caregivers provided for all of his care and comfort needs around the clock with direction from hospice, so that his family could focus on being with him and sharing his final days without worrying about also providing all of his care. Hospice was also able to provide spiritual support for Mr. J and grief support for his family. Mr. J was able to remain home, was kept comfortable and was able to die with dignity and peace in his preferred setting surrounded by his family.

How Matrix Can Help

- Matrix RN Care Managers are knowledgeable about Advance Directive preparation and can provide guidance and assistance in effectively completing health care documents. In addition, Matrix RN Care Managers can help clients identify their preferences and choices for delivery of care, finding and obtaining needed resources, naming end-of-life preferences, developing client focused plans of care and coordinating services.
- Matrix RN Care Managers and Home Caregivers understand the dying process, the special care needs of the person who is dying, emotional support for the dying person and their family and promotion of comfort and quality of life while caring for those who are dying. Because Matrix Care Managers are knowledgeable about palliative care and hospice care services and the agencies that provide them, they can facilitate the process for initiating and providing services chosen by informed clients and families. In addition, Matrix RN Care Managers and Home Caregivers have received special training in provide care for people with serious illnesses, complex medical needs, late state dementia care and end of life care.

For more information about Matrix Home Health Care Specialists or for a complimentary consultation, call 952-525-0505 or 800-560-0961