

## UNDERSTANDING HOSPICE CARE FOR SOCIAL WORKERS

### Goals of course

At the end of this workshop participants will be able to:

- Define hospice care
- Understand palliative vs. curative care
- Identify common misconceptions about hospice care
- Identify social work interventions to assist families in need of hospice care

### **INTRODUCTION**

Death is part of life. Yet there is tremendous resistance in our country to discuss issues surrounding death and dying. This resistance is shared by professional social workers, as we are part of this culture of denial. We have been conditioned to deny death and the perceived stigma associated with a terminal diagnosis.

This course will provide basic information about hospice and identify psychosocial issues associated with dying patients and their families.

In addition, Florida Licensed mental health providers may substitute this end of life course for the Domestic Violence licensure requirement.

### **DYING IN AMERICA**

*Dying is an integral part of life, as natural and predictable as being born. But whereas birth is cause for celebration, death has become a dreaded and unspeakable issue to be avoided by every means possible in our modern society.* (Elisabeth Kubler-Ross, 1969)

There are nearly 40 million senior citizens in the United States. But in the next 30 years, that number is expected to double to 80 million as Baby Boomers and their parents reach age 65. And each year, one-third of the people who die suffer from a chronic illness. For every one of these deaths, there is a patient and a family faced with difficult decisions about care at the last stage of life.<sup>1</sup>

Prior to the early part of the twentieth century, eighty percent or more Americans died in their homes. By the 1940's however, with the advances in pharmacology and medical technology, the setting of death changed to that of hospitals and institutions. Today only twenty percent die at home though ninety percent state that they want to do so, cared for and surrounded by family, friends and/or professional health care providers. What is occurring in the United States does not reflect what Americans actually want.

Because death has been removed from the home most caregivers and mental health professionals are familiar with death from a clinical perspective only. Through understanding of the hospice movement and the needs of the dying patient and their

families, we will be better prepared as a profession to assist them through this important phase of life.

Due to lack of knowledge of available resources, misconceptions and fears, and societal taboos regarding public discussion of the concrete and emotional effects of illness and death, there is also a significant underutilization of the services available through hospice care. Specifically, the reluctance of individuals and families to avail themselves of the services provided by hospice and through the federally funded Medicare hospice program results in underutilization of this valuable end of life care option.

It is significant to note that seventy-five percent of Americans do not know that hospice care can be provided at home and forty-four percent do not know how hospice is paid for.<sup>2</sup>

The National Hospice Foundation commissioned a research study, conducted April 1999, of Americans 45 years of age and older who face care decisions for their aging parents, as well as for themselves, while parenting their own children.

This study revealed that about one-third of Americans are unsure about whom to contact to receive the best care during life's last stages. Thirty percent said they would contact their doctor, thirteen percent mentioned hospice and eleven percent mentioned their family. But nearly one-third said they did not know whom they would contact.<sup>3</sup>

### **HOSPICE: A HISTORICAL PERSPECTIVE**

The word “hospice” derives from the Latin word “hospes”, which meant host or guest. In medieval times, hospices in England, France, Italy, and other European countries served as inns, often provided by religious orders, for weary travelers including those who were on hazardous journey to Africa, Asia and the Middle East.

The first recognized facilities for the dying were Our Ladies Hospice for the Dying, Dublin, founded in 1879 and St Joseph’s in London, 1905.

The modern definition of hospice – an interdisciplinary concept of providing comprehensive care to terminally ill - originated in England with the establishment of St. Christopher’s London, 1967. The name was first applied to specialized care for dying patients in 1967 by physician Dame Cicely Saunders, who founded the first modern hospice—St. Christopher’s Hospice—in a residential suburb of London. Great Britain developed hospices primarily as freestanding, inpatient facilities for the care of the terminally ill.

In 1969 Dr. Elizabeth Kubler-Ross published *On Death and Dying*, a book based on more than 500 interviews with dying patients. The book became an internationally known best seller. Perhaps the greatest impact of this work was Kuhbler-Ross’s plea for home care as opposed to treatment in an institutional setting. She also advocated patients’ rights in having the choices and abilities to participate in the decisions that affect their destiny.

Through efforts of individuals like Kubler-Ross and Senators Frank Church and Frank Moss, who introduced the first hospice legislation, the hospice movement evolved in this country in the late 1970's. In the United States hospices became coordinated programs combining home care with inpatient beds that would meet the needs of patients within the specific community being served, as opposed to the British model that was mainly in-patient settings.

Today there are more than 3,200 hospice programs in the United States, Puerto Rico and Guam. However, 2.4 million Americans died in 2001, while hospice programs cared for nearly 775,000 people that same year.<sup>4</sup>

As interest and support for the hospice movement grew, the Medicare Hospice Benefit was established in 1982. In 1986 the Medicare Benefit was made permanent by Congress and states were given the option of including hospice in their Medicaid programs. Hospice care was also then made available to terminally ill nursing home residents.

### **UNDERSTANDING HOSPICE CARE**

There are many misconceptions and myths about hospice care. It is important to note that the hospice philosophy affirms life – not death. A hospice interdisciplinary team strives to maximize quality in living while offering care and support to the patient and family unit. As clinical social workers, we can help dispel these myths to our clients and the public, so that more individual can avail themselves of this benefit.

The term “hospice” is frequently associated with a specific place. However, hospice is a concept. Hospice care is provided anywhere a patient resides. About 80% of hospice care takes place at home. Although some hospice organizations provide a residence for patients, the term hospice has a much broader definition.

Unfortunately even those individuals who do elect hospice care wait until the final days of their lives. This is reflected in statistics on hospice length of stays. At present, hospice serves only 17-20% of Americans in their dying and serves them for a decreasing length of time.<sup>5</sup> One of the factors in late stage admissions to a hospice program is the reluctance of physicians to refer patients to this service. This may be due to the physician's lack of knowledge about hospice care and also their training which is focused on saving lives.

In 2001, 34% of those served by hospice died in seven days or less, and 6% died in 180 days or more. The average length of service (ALOS) was 48 days; the median length of service (MLOS) was 20.5 days. MLOS is a more accurate way to understand the experiences of hospice patients, due to the high frequency of short stays. In 2001, 94.5% of the days of services were routine home care, 4.3% of the days were inpatient care, 0.4% was respite and 0.8% was continuous home care. Upon admission, 81% claimed hospice Medicare days as their payment source, 5% reported Medicaid days. 11% private insurance days, 1% self-pay and 2% cite alternative sources. Other payment

sources may include, (but are not limited to) Worker's Compensation, Home Health Benefits, and donations from private sources and foundations. In addition, hospice providers receive an average of 13.6% of their revenues from non-reimbursement sources.<sup>6</sup>

Moreover, demographic data suggests that hospice in the United States is still primarily serving adult Caucasians with advanced cancer. Those under served by hospice include: persons of color; non-English speaking people; those who reside in inner cities or in isolated rural areas; those who are living with far advanced pulmonary disease, liver disease, renal failure, heart failure, or dementia; and those with dual diagnoses that include addictions, developmental disability or serious mental illness.<sup>7</sup>

Hospice care is not just for individuals who are in the last stages of the dying process. Medicare guidelines state, "in the physician's best judgment patient is in the end stages of illness." Once a physician has certified that a patient's condition is terminal, they qualify for the hospice benefit and may enjoy many months of that specialized care for themselves and their families, enhancing quality of life.

Initially hospice care was primarily used by cancer patients in this country. Now, more than one-fifth of hospice patients nation-wide have diagnoses other than cancer. Increasingly, hospices are also serving families coping with the end stages of diseases like HIV/AIDS, emphysema, Alzheimer's, cardiovascular and neuromuscular diseases.

It is also crucial to understand that hospice services are not just for the dying patient. As a family-centered concept of care, hospice focuses as much on the grieving family as on the dying patient. Hospice bereavement services continue for at least year for survivors, and longer if needed. Most hospices make their grief services available to the community at large, serving schools, churches, workplaces and providing critical incident debriefings when needed.

Although the majority of hospice patients are over 65, hospices serve patients of all ages. Hospices offer clinical staff with expertise in pediatric hospice care and bereavement staff trained to work with children and adolescents as well as the older or middle-aged patient.

Many people believe that patients must have a caregiver, family or friends, in order to receive hospice services. A patient can be living alone, but at some point will most likely require a caregiver. Recognizing that terminally ill people may live alone, or with a compromised family member who is unable to provide care, hospice social workers coordinate community resources to make home care possible. The social workers help find an alternative location where the patient can safely receive care, such as an assisted living or skilled nursing facility.

## **HOSPICE MEDICARE BENEFIT**

The 1999 NHF research showed that 90% of Americans did not know that Medicare benefits are available to pay for hospice care.<sup>8</sup> Since most people who use hospice are over 65 they are entitled to the Medicare Hospice Benefit.

The Medicare benefit covers virtually all hospice services and requires little, if any, out-of-pocket expense. This means that there are no financial burdens incurred by the family, in sharp contrast to the huge financial expenses at the end of life, which are incurred when hospice is not used.

Twenty-eight percent of all Medicare reimbursements go towards the care of people in their last year of life; almost fifty percent of those costs are incurred in the last two months of life.<sup>9</sup>

A 1998 study conducted by the health care Financing Administration showed savings of \$1.26 for every Medicare dollar spent on hospice.<sup>10</sup>

The Medicare Hospice Benefit covers the following hospice services in full:

- Skilled nursing visits
- Volunteer Services
- Physician visits
- Skilled therapy
- Home health visits
- Medical social services
- Spiritual counseling
- Nutrition counseling
- Bereavement support for the family
- Durable equipment and supplies

The Medicare Hospice Benefit also covers 95% of the cost of the following, although most hospices do not collect the 5% co-payment:

- Drugs for pain and other symptoms
- Inpatient respite care

The Medicare hospice benefit also eliminates the burden of paperwork, as families are not required to submit claims or pay co-payments. The financial burdens often associated with end of life care can be devastating, and the Medicare Hospice Benefit not only assists the patient and family financially, but emotionally as well.

For patients without hospice insurance, financial accommodations are made based on ability to pay.

Another point of confusion for patients is the misconception that once a patient elects Hospice they must give up their Medicare benefit. Hospice Medicare does not replace Medicare benefits for any other care not related to the terminal illness.

Approximately 43 states and the District of Columbia offer hospice coverage under Medicaid, including Florida. Many private health insurance policies and HMO's offer hospice coverage and benefits. Additionally, hospice services are covered under Champus/Tricare.

Patients and their families need to be educated that regular Medicare coverage is still available to Hospice beneficiaries for non-terminal related services.

The Medicare hospice benefit also covers in-patient respite care to relieve the care giving responsibility of the family. The Medicare Hospice Benefit does not cover 24-hour care, but during a medical crisis does provide for continuous care home nursing and short-term in patient services.

### Eligibility Criteria

Medicare has three key eligibility criteria:

1. Two physicians must certify that a patient is terminally ill and thus eligible for hospice care. The patient's doctor and the hospice medical director use their best clinical judgment to certify that the patient is terminally ill if the disease runs its normal course;
2. Admission is voluntary. The patient chooses to receive hospice care rather than curative treatments for their illness.
3. The patient enrolls in a Medicare-approved hospice program.

### **HOSPICE AND PAIN RELIEF**

Because hospice care is associated with pain and symptom relief, often individuals believe that hospices only use narcotics, such as Morphine to control pain and other symptoms. Hospice uses interdisciplinary approaches that utilize both pharmacological and non-pharmacological interventions.

There is a great range of services provided by most hospices, not limited to pharmacological interventions. Social workers play a vital part of the hospice team, providing support and concrete services to the patient and family. Many hospices are including such complementary services such as massage therapy, aromatherapy, therapeutic touch and art and music therapies.

Thus it is important to recognize that the hospice concept is a life-affirming philosophy that regards dying as a natural process that should be neither hastened nor prolonged and that can be met with richness of spirit. Hospice workers strive to maximize quality in living and embrace a philosophy of caring which respects and values the dignity and worth of each person.

It cannot be overemphasized that hospice care, like good social work, is patient directed, with the patient and family being the decision makers. The interdisciplinary team keeps the focus on the entire family as the unit of care, assuring client autonomy and dignity.

## **PALLIATIVE CARE**

The term palliative care is often associated with hospice services. Although the two labels are often thought to be virtually synonymous, but there are distinctions.

The World Health Organization (WHO) defines palliative care as “the active, total care of patients whose disease is not responsive to curative treatment. Control of pain and other symptoms and providing psychological, social and spiritual support are paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families.”<sup>11</sup> The WHO definition goes on to add that, “Many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with anti-cancer treatment.

The word "hospice", as it is currently used in the United States refers to a specific, programmatic model for delivering palliative care. Hospice care, therefore, constitutes a subset of palliative care.

Palliative care is comprehensive care for people with life-limiting illness. It is a team approach focusing on the needs of ill persons and their families. Palliative care is valuable at any time during a serious illness, and one does not have to be terminal to benefit. Patients can continue to fight their disease, while palliative care focuses on improving their quality of life. Hospice is one form of palliative care. Like hospice, palliative care can be provided in a variety of settings including hospitals, nursing homes, and a patient's home.

Currently, in order to receive hospice care, a doctor has to certify that a patient's condition is terminal and both patient and doctor must agree to forgo further surgery, radiation or chemotherapy directed at prolonging life. However, radiation and chemotherapy may be used for hospice patients if the goal is palliative comfort. Palliative care attempts to avoid these conditions and seeks to serve people earlier in the course of illness.<sup>12</sup>

Palliative care may be taken as the broader term, covering all forms of the prevention and treatment of suffering, while “hospice”, in a narrow medical sense is viewed as a subset of palliative care especially targeted to the needs of those near death.<sup>13</sup>

Palliative care should not signal the cessation of various forms of medical treatment potentially beneficial to the patient that might lengthen the duration of life or improve the quality. And hospice should not signal the cessation of hope, but simply a shift of its focus.

Thus, “palliative care” is used to refer to the addition of symptom control and pain management services with the mainstream health care system, whereas “hospice” is used to refer to a structurally and organizationally distinct subsystem that has grown up around the creation of hospice agencies.

When palliative care is used in conjunction with hospice services it is a type of treatment that neither hastens nor postpones death. Palliative hospice care provides relief from pain and other distressing symptoms at end of life and integrates the psychological and spiritual aspects of patient care.

### **STANDARDS OF CARE**

There are certain mandatory standards that a hospice must provide. Foremost is access. Hospices need to provide 24-hour availability of clinical staff for patients and their families. There needs to be an immediate response to urgent issues when the patient or family caregiver calls. And individuals requesting hospice services need to be able to access those services regardless of ability to pay.

Hospice workers must provide patients and family with educated, informed choices as a hospice team does not assume an authoritarian stance, but works with the family for the patient’s best interests. In many cases, the hospice team must provide adequate training to the family to allow them to care for the patient at home.

Symptom management, especially pain management, is crucial. One of the greatest fears of most people is dying in pain and pain relief is possible in most cases.

When patients need to be transferred, whether to skilled care facilities or out of state, the social workers task is the effect a smooth transition and assure that there will be adequate continuity of care for the patient and family.

### **PSYCHOSOCIAL END OF LIFE ISSUES**

Many individuals do not utilize hospice services until the final days of their illness, although the eligibility criteria allows for patients who have a terminal diagnosis to be admitted to hospice care. These are un-served patients who are still functioning at a high level when they enter a hospice program. These patients may still be able to work, enjoy many activities and even travel. By having a longer timeframe to deal with end of life issues, the social worker can make a more significant impact on the dying process for the patients and families.

The following are six specific psychosocial concerns that occur frequently in clinical hospice settings.

1. Loss of Sense of Self

Individuals are much more than the physical dimension, yet it is the physical self that is often the focus of traditional medicine. The hospice philosophy embraces the whole person in their environment and the clinician's task is to understand that person as much as possible in order to assist them with their unique journey towards death. A person's sense of self is derived from many factors including family, work, religion, culture, and community involvement. Some dimensions of a person's self-concept are less apparent as they reflect their internal life such as dreams, aspirations, memories values and regrets.

As death approaches people grapple with their various role changes. People become more aware of losing their sense of self, their identity. Once they can no longer work and support their families or fulfill their role as a parent, they begin to grieve these losses. Some patients experience significant depression, which may not be about their impending death, but their loss of abilities and a coming apart of their self-concept as a valuable person. Through interventions such as life review, the social worker can help the patient sort through the meaning of their lives and assist them in grieving these losses. In some instances, patients begin to find a sense of peace as they are able to let go of their preconceived notions of self, and begin to complete tasks such as completion of significant relationships by being able to forgive and ask for forgiveness and give and receive love.

## 2. Dying Alone

The fear of the actual dying process is greater for most people than the actual fear of death. Pain is the primary factor in most individual's mind, but there is also the fear of loss of independence and how their death will affect loved ones. In Florida, where so many elderly patients are without family and friends, they often express the fear of dying alone.

Many hospices provide "vigil" services for patients who do not have family or friends to be with them at the end of their lives. This service, often provided by hospice-trained volunteers, provides someone to sit with the dying patient so they will not die alone. This service often can provide great comfort and support to the patient as well as family members who may not be able to be present during the last days.

## 3. Financial Concerns

The hospice social worker also attempts to help patients resolve financial concerns, from discussing and helping make funeral arrangements to how the family will survive after the patient's death. These types of concrete tasks can also pave the way for a therapeutic alliance, as the patient and family see the social worker as an effective advocate and information source.

For younger patients who are not eligible for the Medicare Hospice Benefit and who lack economic resources, the social worker can assist them in accessing Medicaid benefits, which cover hospice care in Florida.

#### 4. Spiritual Issues

Spiritual issues are generally handled by hospice chaplains. They receive specialized training in end of life care. However, there is a growing trend in social work practice to recognize and validate spiritual issues. As patients sort through their values and attempt to find meaning in their lives, social workers can provide supportive listening, validation of feelings and reflection. Often the most important intervention the clinician provides is to be quiet and “present” with the patient. Non-verbal support can be more potent than words, which are frequently inadequate or unnecessary to the material presented by the patient.

#### 5. Loss of Independence

As the person enters the last phase of their illness, increased weakness and fatigue are common symptoms. The patient will have greater need for assistance with their activities of daily living. This can produce emotional stress, especially for individuals who have always been independent. Providing assistance with activities of daily living can be a source of shame, for example the dying mother who now relies on her adult son to assist her with toileting and bathing. Many families are initially reluctant to utilize home health aides, as they want to “do it themselves”. While it can be a comfort for some families to provide tasks such as bathing, it can also be exhausting and decrease their ability to spend quality time with the patient. Helping families understand how services like home health aides can provide respite for the caregiver is another frequent intervention of the hospice social worker.

#### 6. Death Preparation

The dying process is unique to each individual. While some may want to spend more time with spouses and family, others become withdrawn and even non-communicative. The social worker can educate the family on the different ways that people approach their death.

For example, the patient who begins to turn away from family and be non-responsive may not be exhibiting symptoms of depression but merely the way in which this patient is choosing to die. Providing this type of education to the families and loved ones helps them understand that this type of behavior does not necessarily reflect the nature of their relationship with the dying person, but merely one way that dying patients may cope with the dying process.

### **COMMON SOCIAL WORK INTERVENTIONS IN END OF LIFE CARE**

The admissions process, discussion of need for food and water, preparation of advance directives and life review are among the most common social work interventions in hospice care.

#### Admissions

Referrals for admission to hospice may come directly from the individual, family, clergy and friends. The hospice intake or referral team will provide information, education and assessment. However, a physician must certify that a patient is terminally ill to admit that patient to a hospice program.

A hospice admission team usually consists of a nurse and social worker. Admission to a hospice program can be a very traumatic moment in the lives of the patient and their families, and one that requires sensitivity and empathy, yet direct communication on the part of the social worker. In many cases, the patient has just been informed, perhaps within a matter of hours or days, by their physician that there are no longer any aggressive treatment options available for them. Because the public often assume that hospice is for “the very last days”, a hospice referral may be devastating to the patient and their loved ones.

It is important to identify the level of patient acceptance and awareness of their terminal diagnosis, as well as that of their significant family members. The paradox of a hospice admission is that while hopes of recovery may be dashed, it is offering hope that the patient can die in comfort and spend their remaining time enjoying as much quality of life as possible. This concept is difficult for many people who still view hospice as “giving up” on life.

During the admission process the social worker attempts to assess the patient’s and family’s previous experiences with death. Many of our current elderly population will have memories of caring for a dying relative at home, before modern medicine and technology brought the dying process to hospitals. During the assessment process, the social worker can look for indicators of possible future complicated grief reactions, particularly in families that have experienced the death of a child, a suicide, or a recent loss.

The social worker interventions during admissions are supportive, reflective and directive. An effective admission will concentrate on education, providing information about what hospice services are available to the patient and families, explaining advance directives and validating the importance of patient self-determination and autonomy.

### Food and Water Issues

Terminally ill patients experience loss of appetite and subsequent weight loss as their illness progresses. The patient’s family sees food not only as necessary for survival, but also as a source of caring, nurturing and comfort.

The social worker will hear comments from caregivers such as, “*She never feels like eating. I try to give her food so that she can keep up her strength.*” While the patient may be saying, “*All they talk about is food, always wanting me to eat more. They don’t understand that I would eat more if I could.*”

While the family members focus on the need for food and insist the patient eat even when she says “no”, the patient rarely becomes concerned about his or her own loss of appetite. This conflict can be emotionally painful to everyone concerned and may lead to friction within the family, adding more stress to the family system as the disease progresses.

During the dying process, dehydration occurs naturally and is not an uncomfortable experience for the patient. Indeed, as the body enters the dying process, forcing food or hydration on a patient can bring more physical discomfort.

However, this can be a very uncomfortable experience for the family, especially families that have traditions and rituals that associate food with love. For the family, this loss of appetite equates to loss of life. Family members need to be educated on the effects of “forcing” the patient to eat. The social worker can provide education to the family by teaching them other ways to nurture their loved one.

The hospice social worker can help facilitate discussion regarding these difficult decisions. They can assist the family in expressing concerns and feelings and help them to clarify their values as part of the decision making process. Once the decision is made by the family and patient, it is the role of the hospice social worker to give their support to that decision.

### Advance Care Planning

Just as the topic of death and dying is difficult for many individuals, so is too is the important issue of Advance Directives

In 1997 the Florida Commission on Aging with Dignity created a document called “Five Wishes.” By answering these five questions, a patient may be better able to formulate his or her advance directives.<sup>14</sup>

<p><b>THE FIVE WISHES</b> The five wishes include:</p> <ul style="list-style-type: none"><li>● the person who I want to make healthcare decision for me when I cannot make them for myself.</li><li>● what kind of medical treatment I want or don't want if I am close to death, in a coma, or have permanent and severe brain damage and am not expected to recover from that condition or am in another condition under which I do not wish to be kept alive.</li><li>● how comfortable I want to be.</li><li>● how I want people to treat me.</li><li>● what I want my loved ones to know.</li></ul>
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Source: Florida Commission on Aging with Dignity, “Five Wishes,” *Aging with Dignity*, 2001. <<http://www.agingwithdignity.org/5wishes.html>> (July 2003)

## Advance Directives Documents

Advance Directives are legal documents that provide instructions regarding medical treatment and care preferences, particularly end of life wishes. Three common forms of advance directives include a living will, a durable power of attorney for health care and a Do Not Resuscitate Order.

A living will is a document that informs doctors and family members about medical care preferences once an individual becomes terminally ill, permanently unconscious or has an end-stage condition.

A durable power of attorney for health care, also known as a health care proxy, is a document, which gives another person power to make medical treatment and related personal care decisions if the individual is unable to make them for themselves.

*The difference between a durable power of attorney for health care and a living will:*

The focus of the durable power of attorney for health care is on who makes healthcare decisions when an individual can no longer do so themselves. A durable power of attorney for health care can be applicable during temporary disability.

The focus of the living will is on what the actual decisions will be regarding medical treatment. A living will is limited to care during the terminal illness, permanent unconsciousness or end stage of condition.

Florida statutes have expanded the use of a “Do Not Resuscitate Order” (DNRO), a special form of advance directive. The DNRO is specific for withholding and withdrawing CPR and must be on a special form provided by the statute. Patients may even wear special tags so all persons who come in contact with them will know what their wishes are. The law provides that when properly executed, the DNRO may be honored by hospital emergency personnel, nursing home staff, assisted living facility staff, home health agency personnel, hospice care teams and adult family home providers. Civil liability protection is extended to include these groups.

Another misconception about hospice care is that all hospice patients must have advance directives. Hospice admission does not require that patients have advance directives, although they must provide education about these documents to patients and their families.

Patients are not required to sign Do Not Resuscitate Orders or complete living wills in order to be accepted at a hospice program. However, upon admission to hospice as well as to hospitals and nursing homes, all patients are given information regarding Advance Directives. Although the Patient Self-determination Act made it illegal to deny a patient admission to hospice because he or she has not agreed to a DNR order, discharge planners still sometimes believe that a DNR order is essentially required for acceptance by a hospice program.

## Advance Directive Concerns

A hospice social worker may encounter several concerns when explaining advance directives to patients and their families. The primary concern regards patient autonomy. It is essential that the patient be fully informed about the nature of these documents to assure that they will not be doing something against their will.

Although many patients welcome these discussions, some patients are not ready. In these cases the social worker does not force the issue, but should be supportive and provide information when appropriate.

Other areas of importance when explaining advance directives to patients include:

- Omitting the proxy from discussion. If the person who is to be designated can be present during education and discussions, that will eliminate future problems or conflicts. The social worker needs to ask proxies if they are able and willing to fulfill their role. For example, the adult child who says, "I want to keep him alive no matter what" would not be able to honor the patient's wishes if they chose to withhold or withdraw life prolonging procedures.
- Not discussing all the options. There are several choices the patient can make when planning advance directives. For example, they may want to continue with feeding tubes, but not be on a respirator. The social worker needs to explain all the options available so the patient can make an informed decision.
- Avoiding it. Again, due to the clinician's own values and beliefs, the task of explaining and helping to execute advance directives may seem too difficult. In this situation, the social worker may need to obtain their own supervision to help them work on strategies and interventions they can feel comfortable with.
- Not informing loved ones/family. In states like Florida, where many hospice patients live far away from loved ones and family, it is important to include family with the decisions. Once the patient has agreed to this communication, the social worker can contact the family. Again, this may help to avoid possible conflict when the time comes that the health surrogate must be appointed.

## Advance Care Planning: The Law and Policy

In the past decade there has been an increase in support for advance care planning by the federal and state legislatures as well as policies of medical organizations. Following is a brief chronology of advance care laws and policies.

US Supreme Court, 1990: Upheld the patient's right to self-determination, establishing that the right applies even to patients who are no longer able to direct

their own health care, and that decisions for incompetent patients should be based on their previously stated wishes.

Federal law, 1991: The Patient Self-determination Act requires that patients be informed of their rights to accept or refuse medical treatment and to specify in advance the care they would like to receive should they become incapacitated.

AMA's Council on Ethical and Judicial Affairs 1997: This body identified advance care planning as an essential component of standard medical care, It called for physicians to conduct advance care planning discussions on a routine basis using advisory documents as an adjunct to statutory documents, such as the living will and the durable power of attorney for health care. The American College of Physicians Ethics Manual, 4th edition, 1998, also supports advance care planning.

Florida Statute 765.10 (2001) states that “any competent adult may designate a health care surrogate or make a living will expressing their wishes regarding withholding/withdrawing medical treatments. The patient’s right to refuse treatment continues even when he/she becomes incapacitated.”

Florida statutes have also been simplified and changed to require only one physician to determine and enter into the medical record that the patient lacks capacity for decision-making.

State Law: Florida has divided the advance directive into two documents: the Florida Designation of Health Care Surrogate and the Florida Living Will. Both documents support the legality and legal enforceability of Advance Directives and healthcare surrogates.

### Life Review

*“The touchstone of dying well -- the sense of growing individually or together in the midst of dying -- is that the experience is of value and meaningful for the person and their family.”<sup>15</sup>*

Life review is a process that assists the patient on several levels. It can be an educative as well as therapeutic process. This intervention allows the patient to identify loss due to disease and express feelings and issues around loss and grief. Exploration of past losses and coping strategies helps reinforces strengths of the patient and family. Education on grief reactions teaches patients and families typical responses to loss and grief. This education can help normalize the feelings and thoughts that they are experiencing and can also assist them with closure.

The process of life review can also provide a sense of meaning about ones' individual life, which many people struggle with at end of life. This is especially true for those with “unfinished” business.

Some view life review as just the telling of "one's stories". However, this simple process can also be a transmission of knowledge and wisdom. Life review can be done on a simple level, with the patient sharing stories about their past and making connections to their present. Alternatively, it can be a more formal process. One technique that is becoming more popular is to have the patient “tell their story” on audiocassette or video tape. This can be a valuable experience for both the patient, as she is able to concretely review the significant, and not so significant, events of her life, and start to find meaning and purpose. For the family and friends a recorded life review can be an enduring legacy after the patient’s death.

### **SUMMARY**

Although the hospice movement is still relatively new in the American health care system, the impact that it is making on improving the experience of dying for patients and their families has been great. Unfortunately, due to the climate of denial and anxiety around discussing death in our culture, there is still much work that needs to be done to educate the public, as well as those in the professional health care professions, on this valuable resource.

As America ages there is also a need for social workers to receive adequate education and training for working with the dying and their families.

As clinical social workers we have the opportunity to help dispel the myths and misperceptions about hospice care, from criteria for admission to the myriad roles that the professional social worker has in helping individuals through this difficult time.

*Hospice makes it possible for patients to live and die with dignity.*

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## PROFESSIONAL WEB RESOURCES

**American Academy of Hospice and Palliative Medicine (AAHPM)** [www.aahpm.org](http://www.aahpm.org)

**American Association of Homes and Services for the Aging** [www.aahsa.org](http://www.aahsa.org)

**American Pain Society** [www.ampainsoc.org/home.htm](http://www.ampainsoc.org/home.htm)

**American Hospice Foundation** [www.americanhospice.org](http://www.americanhospice.org)

**Caregiver.com** [www.caregiver.com](http://www.caregiver.com)

**Center to Advance Palliative Care (CAPC)** [www.capcmssm.org](http://www.capcmssm.org)

**Hospice Cares** [www.hospice-cares.com](http://www.hospice-cares.com)

**The International Association for Hospice and Palliative Care (IAHPC)**  
[www.hospicecare.com](http://www.hospicecare.com)

**Hospice Foundation of America** [www.hospicefoundation.org](http://www.hospicefoundation.org)

**National Association of Professional Geriatric Care Managers**  
[www.caremanager.org](http://www.caremanager.org)

**National Family Caregivers Association** [www.nfcacares.org](http://www.nfcacares.org)

**National Hospice and Palliative Care Organization** [www.nhpc.org](http://www.nhpc.org)  
NHPCO's toll-free Helpline at (800) 658-8898 or log on to [www.nhpc.org/  
database.htm](http://www.nhpc.org/database.htm).

**Pain.com** [www.pain.com](http://www.pain.com)

**World Health Organization** [www.medsch.wisc.edu/painpolicy](http://www.medsch.wisc.edu/painpolicy)

## COMMUNITY END OF LIFE WEB RESOURCES

**AgeNet, LLC** [www.agenet.com](http://www.agenet.com)

**Aging with Dignity** [www.agingwithdignity.org](http://www.agingwithdignity.org)

**The American Institute of Life-Threatening Illnesses** [www.lifethreat.org](http://www.lifethreat.org)

**Before I Die** [www.wnet.org/archive/bid/index.html](http://www.wnet.org/archive/bid/index.html)

**Dying Well** [www.dyingwell.org](http://www.dyingwell.org)

**The End of Life: Exploring Death in America** [www.npr.org/programs/death](http://www.npr.org/programs/death)

**Education for Physicians on End-of-Life Care (EPEC)** [www.ama-assn.org/ethic/epec](http://www.ama-assn.org/ethic/epec)

**Innovations in End-of-Life Care** [www.edc.org/lastacts](http://www.edc.org/lastacts)

**Last Acts** [www.lastacts.org](http://www.lastacts.org)

**Medicaid Information** [www.hcfa.gov/medicaid/medicaid.htm](http://www.hcfa.gov/medicaid/medicaid.htm)

**Medicare Rights Center** [www.medicarerights.org](http://www.medicarerights.org)

**Promoting Excellence in End-Of-Life Care** [www.endoflifecare.org](http://www.endoflifecare.org)

## NOTES

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<sup>1</sup> National Hospice & Palliative Care Organization, *NHPCO Facts and Figures*, (Alexandria, Va., January 2003.) <<http://www.nhpco.org/>> (June 2003)

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<sup>5</sup> Kinzbrunner, Barry, MD FACP , *The Medicare Hospice Benefit*, (American Academy of Hospice and Palliative Care, Glenview, Il., Spring, 2002) [http://www.aahpm.org/resources/bulletin/aahpm\\_spring01.pdf](http://www.aahpm.org/resources/bulletin/aahpm_spring01.pdf) (June 2003)

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<sup>13</sup> National Hospice & Palliative Care Organization , *NHPCO Facts and Figures* (Alexandria, Va., January 2003) <<http://www.nhpco.org/>> (June 2003)

<sup>14</sup> Florida Commission on Aging with Dignity, “Five Wishes,” *Aging with Dignity*, 2001. <<http://www.agingwithdignity.org/5wishes.html>> (July 2003)

<sup>15</sup> Byock, I, *The Nature of Suffering and the Nature of Opportunity at the End of Life*, *Clinics in Geriatric Medicine*, Vol. 12, pp 237-251, May 1996. <[www.dyingwell.org/sugg-opp.htm](http://www.dyingwell.org/sugg-opp.htm)> June 2003.

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## UNDERSTANDING END OF LIFE CARE

### True/False

- Hospice is a place.                      True                      False
- Hospice care is most effective during the last few days of life.            True    False
- Hospice only takes care of cancer patients.    True                      False
- Palliative care is an approach used by hospices.            True                      False
- A patient must have a caregiver to receive Hospice services.            True    False
- Once a patient elects the Medicare Hospice Benefit they still retain Medicare coverage for non-terminal related health care.            True                      False
- Hospice patients should be educated about advance directives during the admission process.    True                      False
- Life review is an important intervention for social workers to utilize with the dying patient.            True                      False
- Hospice patients may not receive any type of radiation or chemotherapy.            True                      False
- All hospice patients must sign a Do Not Resuscitate Order before admission to a hospice program.    True                      False

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Use the form below to either mail, fax, or email your registration End of Life Care

**Michael Freeny Associates**  
**5764 N. OBT, Suite 128 Orlando, FL 32810**  
**407-884-6553 (voice/fax)**

You may also email your request to [mfreeny@clinicalCE.com](mailto:mfreeny@clinicalCE.com). Payment can be made by check, Visa or MasterCard or online. You will be billed for **\$25.00**. You must return the evaluation form before your certificate of attendance can be mailed out (a Board requirement). You may include this form for payment.

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