End-of-Life Care

LEARNING OUTCOME AND OBJECTIVES: Upon completion of this continuing education course, you will have improved your knowledge of end-of-life care. Specific learning objectives include:

- Discuss the current status of end-of-life care in the United States.
- Differentiate between palliative care and hospice care.
- Explain the principles and ethical challenges of end-of-life care and hospice.
- Discuss the essential elements of effective communication with patient and family.
- List pharmacologic and nonpharmacologic comfort measures for the dying patient.
- Identify the psychological and emotional needs of the patient and family.
- Describe the special end-of-life care needs of children, veterans, and terminal patients with cancer, dementia, and HIV/AIDS.
- Describe care of the patient during the last hours of life.
- Explain the steps in postmortem care.

THE NEED FOR END-OF-LIFE CARE

The Burden of Chronic Illness

According to the Agency for Healthcare Research and Quality (AHRQ, 2015a), two thirds of Americans over age 65 have two or more chronic physical or behavioral health illnesses. In an ongoing effort to improve their care, the AHRQ has partnered with the U.S. Department of Health and Human Services (DHHS) to research and monitor those with multiple chronic illnesses to suggest strategies for better outcomes. Eighty-six percent of all healthcare funding...
pays for the treatment of chronic diseases. Seventy percent of all deaths among Americans are from chronic diseases (CDC, 2016a).

The graying of the Baby Boom generation (born 1946 to 1964) threatens to intensify this burden of chronic illness. The oldest baby boomers have already turned 70, and the older population of the United States is beginning to increase. According to the most recent statistics available from the DHHS Administration on Aging (2016), the age-65-and-older population reached 46.2 million in 2014, comprising 14.5% of the total population. Research has also shown that baby boomers are living longer than people roughly 20 years older but that they are not healthier. They are less likely to smoke, have emphysema, or heart disease; but they are more likely to be obese and/or have diabetes and/or high blood pressure than the previous generation.

The burden of chronic illness and the ongoing epidemics of cancer and HIV/AIDS point to an exponential escalation in the demand for palliative care over the next several decades. In 2050, the population aged 65 and over is projected to be 83.7 million, almost double their population of 43.1 million in 2012 (Ortman et al., 2014). Experts are concerned that there will be too few physicians and nurses certified in palliative care to meet the needs of this aging cohort.

Boomers make up a significant part of the healthcare workforce as well. Nearly 40% of nurses will retire by 2030 and will be seeking more healthcare themselves. Nurses in their 50s will be the largest segment of the nursing population. When these health professionals who are baby boomers retire, the existing nursing shortage will worsen (Brooks, 2016).

In 2014, a total of 2,626,418 resident deaths were registered in the United States (Kochanek et al., 2016). While 10% die suddenly in an accident or from a fatal heart attack or stroke, most people require care over weeks or months as their health diminishes. On average, Americans with chronic illness will need help with routine activities of daily living for two or more of their final years of life.

Up to 72% of people in the United States would prefer to be cared for and die at home, but only 21% do. Fifty-three percent die in hospitals and one fourth die in long-term care facilities. Far too many die in pain; many experience significant pain in the last month of life (Kmietowicz, 2015).

Dying in hospitals not only increases the cost of care but often subjects patients to uncomfortable and unnecessary procedures. For example, increasing numbers of elderly patients are being admitted to intensive care units, where they require ventilator assistance, tracheotomies, aggressive treatment for sepsis, suctioning, catheterization, more frequent monitoring and interventions, and an upsurge in diagnostic tests (Battle et al., 2014).

**Lack of Knowledge about End-of-Life Care**

In general, Americans are reluctant to talk about death or to express their wishes about end-of-life care. Less than one third of Americans express in writing their wishes about how they want to be cared for at the end of life. Fewer still have not thought about end-of-life care at all, while some have thought about it but not told anyone what they want.
Avoiding the subject of death has created woeful ignorance about end-of-life issues, resulting in less than optimum care and diminished quality of life for the dying and their families. For instance, research by the National Hospice and Palliative Care Organization (NHPCO, 2015) showed that 75% of Americans do not know that hospice care can be provided in the home. The Medicare hospice benefit, instituted in 1983, guarantees comprehensive, high-quality care at little or no cost to terminally ill Medicare beneficiaries and their families. Hospice is paid for by Medicare funds in 85.5% of all cases.

Many people also think hospice care means “giving up” and that it will shorten survival. Likewise, patients, families, and some physicians believe that trading aggressive treatment of potentially fatal conditions for improved quality of life may decrease patients’ lifespans. However, in recent studies into the effects of early palliative care, one showed a 19.5% increase in patients’ lifespan over those patients not receiving palliative care; another detected a 31% increase; and at worst, another revealed no significant difference between survival rates between terminal patients who died in acute care facilities and those who died at home. Such results replicate previous studies that found early palliative care both improving quality of life and extending life (Hamano et al., 2016).

To educate the public about the need to plan for end-of-life care, in 2009 healthcare reform advocates drafted a provision for Medicare reimbursement for physician-patient discussions of advance directives. Opponents of healthcare reform and sympathetic media labeled this type of patient education as “death panels,” effectively killing the measure (Frankford, 2016).

**PALLIATIVE CARE VERSUS HOSPICE CARE**

The terms palliative care and hospice care are often confused or mistakenly used interchangeably, but they have different meanings. Both palliative and hospice care aim to improve a patient’s quality of life and comfort by preventing and relieving symptoms. However, palliative care can be provided at any stage of illness and concurrent with curative treatments, whereas hospice care is provided only at the end of life when curative treatments have been stopped.

For instance, a patient with curable cancer may receive palliative care to address pain, stress, and other symptoms alongside their curative treatments of radiation therapy. And a patient whose end-stage cancer is no longer responding to treatment may receive hospice care once they have received a terminal diagnosis and ended all treatments for the remaining weeks or months of life.

**Trends in End-of-Life Care**

In our death-denying culture, both the public and health professionals tend to regard death as a failure of the medical system rather than a normal stage of life. This view is a modern phenomenon, however. Before the advent of modern hospitals, antibiotics, vaccines, and life-sustaining technologies, death came quickly after an accident or serious illness. Families cared
for the dying at home, including preparation of the body for burial, a function now performed by the funeral industry.

In more recent years, death began to emerge from the closet when the first modern hospice opened in England in 1967. Dame Cicely Saunders, educated first as a nurse and then as a physician, is considered the founder of the modern hospice movement. The first hospice in the United States, the Connecticut Hospice, Inc., initiated in-home services in 1974.

Elisabeth Kübler-Ross pioneered multidisciplinary seminars on death and dying. Her now-classic book *On Death and Dying*, published in 1969, found a ready audience among professionals as well as the public. Healthcare curricula slowly began to change, first in nursing and later in medicine, to include content on care of the dying.

Evidence that end-of-life care is changing in the United States includes:

- The number of hospice programs has grown to approximately 6,100, and most are certified by Medicare. Hospice is increasingly available in long-term care facilities and hospitals.
- Hospice care is available in all 50 states, the District of Columbia, Puerto Rico, Guam, and the U.S. Virgin Islands.
- More people are choosing hospice care: In 2014, 1.6 to 1.7 million people received services from hospice, representing 62.8% of all deaths in the United States.
- Over 58% of hospice patients receive hospice care at home rather than in an acute-care hospital or inpatient hospice.
- Hospice services are covered under the federal Medicare health insurance program and, in 46 states, by the joint federal-state Medicaid program. The Medicare hospice benefit covered 85.5% of hospice patients in 2014 (NHPCO, 2015).
- Military personnel and their dependents are covered for hospice care. All U.S. veterans have hospice benefits through the Veterans Administration (DVA, 2016).

Despite some encouraging changes, other significant challenges remain. Hospice services are still not as widely used as they could be. Fewer than half of patients eligible for hospice choose that option, and the median length of stay in hospice is only 17.4 days, far less than the 60 days considered necessary for people to gain maximum benefit. Approximately one third (35.5%) of dying patients have hospice care for a week or less (NHPCO, 2015).

A 2009 Center for Medicare and Medicaid Services rule initiated a seven-year phase out of the Budget Neutrality Adjustment Factor for calculating the Medicare hospice wage index. This will result in an eventual 4.2% reduction in hospice reimbursements. The Affordable Care Act will further reduce the Medicare hospice rate formula through a “productivity adjustment factor” that will reduce hospice payments by an additional 11.8% from 2015 to 2025 (HAN, 2016).
<table>
<thead>
<tr>
<th>Grade</th>
<th>Hospitals with Palliative Care Programs (percentage by state)</th>
</tr>
</thead>
<tbody>
<tr>
<td>“A”</td>
<td>Montana, 100% New Hampshire, 100% Vermont, 100% Washington, 92.7% Nevada, 91.7% New Jersey, 91.2% Oregon, 88.9% Rhode Island, 88.9% South Dakota, 88.9% Massachusetts, 87.8% Wisconsin, 87.7% Maryland, 87.5% Nebraska, 87.5% Utah, 84.6% Connecticut, 84% Ohio, 82.8% Minnesota, 81.6%</td>
</tr>
<tr>
<td>“B”</td>
<td>Maine, 78.6% New York, 78.1% Virginia, 76.9% Colorado, 75.7% Delaware, 75% California, 74% Illinois, 72.1% District of Columbia, 71.4% Hawaii, 70% Arizona, 68.4% Pennsylvania, 68.3% Indiana, 67.7% Idaho, 66.7% Iowa, 66.7% Michigan, 66.7% Missouri, 66.7% North Dakota, 66.7% North Carolina, 65.3%</td>
</tr>
<tr>
<td>“C”</td>
<td>Florida, 58.1% South Carolina, 58.1% Tennessee, 56% Louisiana, 55.8% West Virginia, 55.6% Georgia, 55.2% Kentucky, 53.1%</td>
</tr>
<tr>
<td></td>
<td><strong>2015 ACCESS TO PALLIATIVE CARE REPORT CARD</strong></td>
</tr>
<tr>
<td>Grade</td>
<td>Hospitals with Palliative Care Programs (percentage by state)</td>
</tr>
<tr>
<td>“A”</td>
<td>Montana, 100% New Hampshire, 100% Vermont, 100% Washington, 92.7% Nevada, 91.7% New Jersey, 91.2% Oregon, 88.9% Rhode Island, 88.9% South Dakota, 88.9% Massachusetts, 87.8% Wisconsin, 87.7% Maryland, 87.5% Nebraska, 87.5% Utah, 84.6% Connecticut, 84% Ohio, 82.8% Minnesota, 81.6%</td>
</tr>
<tr>
<td>“B”</td>
<td>Maine, 78.6% New York, 78.1% Virginia, 76.9% Colorado, 75.7% Delaware, 75% California, 74% Illinois, 72.1% District of Columbia, 71.4% Hawaii, 70% Arizona, 68.4% Pennsylvania, 68.3% Indiana, 67.7% Idaho, 66.7% Iowa, 66.7% Michigan, 66.7% Missouri, 66.7% North Dakota, 66.7% North Carolina, 65.3%</td>
</tr>
<tr>
<td>“C”</td>
<td>Florida, 58.1% South Carolina, 58.1% Tennessee, 56% Louisiana, 55.8% West Virginia, 55.6% Georgia, 55.2% Kentucky, 53.1%</td>
</tr>
</tbody>
</table>
Disparities in End-of-Life Care

Where Americans die is influenced not only by race/ethnicity and socioeconomic status but also by cultural and spiritual/religious beliefs and by where people live. Access to palliative care and hospice programs varies from state to state and between rural and urban populations.

GEOGRAPHIC DISPARITIES

Recent statistics show that more than 53 million people live in rural America. People living in rural counties have limited access to hospice and palliative care. Rural residents are more likely to be older, poor, and to have a higher incidence of chronic disease. Factors that determine whether a Medicare-certified hospice is available in rural counties include physician availability and minority composition of the county. Rural residents are more dependent on public health and social support programs, but their access to healthcare is geographically limited. Home healthcare and hospice providers in rural areas face pressures as the only provider model to deliver services at the patient’s home. There are the added challenges of distance, weather, geographic features, and gas prices (Franckhauser, 2013).

A nationwide survey of the 6,100 certified hospice programs in the United States revealed wide geographic variation in the prevalence of these programs (NHPCO, 2015). Discrepancies also exist in the provision of palliative care (see table above).

RACIAL/ETHNIC DISPARITIES

Disparities between white and nonwhite populations exist across the spectrum of healthcare, including end-of-life care. One study of Medicare beneficiaries of all racial/ethnic groups found that most express a wish to die at home in the event of a terminal illness and not to receive life-prolonging drugs or mechanical ventilation. However, black families were less likely than whites to receive information about what to expect during end-of-life care. Both blacks and Hispanics were more likely than whites to prefer spending their last days in the hospital. Hispanics were less likely than whites to have their wishes adhered to while in hospice and more likely to receive less pain medications (AHRQ, 2015b).
National statistics studying the use of hospice care by race and ethnicity found that blacks (7.6%) and Hispanics (7.1%) used hospice services significantly less than white patients (76%) (NHPCO, 2015).

Other disparities in end-of-life care include lack of adequate pain care in minority patients and poor management of pain by healthcare practitioners. Hispanics and non-Hispanic blacks are more likely to report more pain sites, worse pain intensity, and higher levels of pain. They were also more likely to have concurrent depression and pain self-efficacy than white hospice patients (Murtaugh et al., 2016).

Other factors contributing to disparities include lack of knowledge about end-of-life care options, mistrust of the healthcare system, and poor communication between clinicians and patients. Hospice care may be perceived as a luxury in some communities, even though Medicare and Medicaid benefits require little out-of-pocket expenditure.

Language differences can lead to misunderstanding and misinformation that affect medical decision-making. For example, hospice may translate to hospicio in Spanish, meaning “orphanage” or “place for poor people or poorhouse” (Reverso Dictionary, 2016). In a study among non-Cuban Hispanics, proficiency with the English language increased use of hospice services by 3.1 times (Park et al., 2016).

Recent studies show minority cultures, such as Latino and African Americans, use hospice services to a lesser degree than white patients. African Americans highly value being cared for by a loved one at the end of life, and this (and a lack of knowledge) may contribute to the lack of use of hospice services (Becze, 2013). Latinos, the largest minority in the country, have a reluctance to discuss death and a strong sense of family, resulting in low use of hospice services (Fernandez, 2013). Cultural factors in the Chinese community emphasize how family members are interconnected rather than acting as individuals. It is also considered presumptive to proactively affect events instead of waiting for natural outcomes (CHCF, 2014).

PALLIATIVE CARE AND HOSPICE

Both palliative care and hospice in the United States originally focused on the care of cancer patients, but now both encompass care of patients with other severe illnesses such as kidney disease or heart disease. Palliative care is a recognized subspecialty by the American Board of Medical Specialties.

Palliative Care

The word palliative comes from the Latin word palliare, which means “to cloak” or “to disguise.” The purpose of palliative care is to reduce the symptoms of a medical condition in order to provide the patient with comfort (Merriam-Webster Dictionary, 2016).
Palliative care has also been defined as follows:

Palliative or supportive care is an alternative to frequent hospitalizations for symptom management in chronic conditions. It is defined as improving quality of life through prevention and relief of distressing symptoms by addressing physical, psychosocial, and spiritual issues while affirming life. Palliative care can and should be used with other treatment modalities early in the chronic disease process and death as normal processes. (McClendon et al., 2015)

Palliative care and hospice care are not the same (see box “Palliative Care versus Hospice Care” above). Palliative care is not limited to end-of-life care. As people are living longer with formerly fatal illnesses, palliative care may be used to keep them comfortable during curative treatments. Unfortunately, referrals to palliative care tend to occur late in the trajectory of illness. This may be related to the misperception of palliative care as synonymous with hospice or end-of-life care.

Palliative care’s focus on communication in addition to pain and symptom management occurs long before the end of life. Primary care providers explore their patients’ values, culture, and goals in deciding how aggressive to be in treating diseases such as cancer and caring for the patient during treatment. Palliative care workers provide social and spiritual support for both the patient and the family in a team-based approach to care delivery.

Patients facing diseases such as HIV/AIDS may live for years. This is why palliative care is necessary for patients with chronic illnesses who want to remain in control of their lives (Boucher, 2016).

The term palliative care may evoke the negative connotations linked to cancer and terminal illness, and palliative care is not routinely included in nursing curricula. Palliative care has, however, progressed from a community-based, hospice movement into a multidisciplinary, inpatient model in hospitals, and medical students, residents, fellows, and oncologists are now mandated to receive palliative care training. Ten percent of the questions on the certification examination for medical oncology focus on palliative care knowledge (Ramchandran & van Roenn, 2013).

As an alternative to the term palliative care, the National Cancer Institute defines supportive care as care given to improve the quality of life of patients with a serious or life-threatening disease. The goal of supportive care is to prevent or treat as early as possible the physical symptoms of the disease; treatment side effects; and psychological, social, and spiritual problems related to the disease or its treatment (NCI, 2016a). Supportive, or palliative, care also includes an assessment of the patients’ goals for care. Deciding when to stop treatment can be difficult and should involve the patient, family, and the healthcare team. However, ending treatment does not mean ending care.

Palliative care for those with life-limiting illness ideally begins at the time of diagnosis. Many people who do not fear death do fear the process of dying, the prospect of pain and suffering, and
being a burden to their families. Research by the NHPCO (2016a) shows that the top priorities for a loved one with terminal illness are:

- To be sure that the patient’s wishes are honored
- Choice among the types of services the patient can receive
- Pain control tailored to the patient’s wishes
- Emotional support for the patient and family

In today’s world, the word family can have more than one definition. In the context of palliative care, the National Consensus Project (2013) stated that:

The family is defined by the patient or, in the case of minors or those without decision-making capacity, by their surrogates. In this context, family members may be related or unrelated to the patient; they are individuals who provide support and with whom the patient has a significant relationship. The care plan is determined by the goals and preferences of the patient and family with support and guidance in decision-making from the healthcare team.

Hospice

All the above-mentioned priorities are available in hospice care, which can act in part as a delivery system for palliative care services. However, hospice requires determination from a physician that an individual’s life expectancy is less than six months. Hospice is considered the gold standard for end-of-life care. The central paradigm of hospice is that each person is entitled to a high quality of life using a holistic approach and that families are entitled to the support necessary to allow that to happen (Ashley & Fasolino, 2016).

Hospice care is based on an interdisciplinary team approach that includes physicians, nurses, spiritual counselors, social workers, home health aides, bereavement counselors, trained volunteers, and speech, physical, and occupational therapists, if needed. The team develops an individualized care plan with family caregivers as shared decision makers to meet each patient’s needs for pain management and symptom control. When the patient is cared for at home, hospice staff is on-call 24 hours a day, 7 days a week (Washington et al., 2016; Zinn, 2016).

Many people mistakenly think that hospice refers to a place. Although there are some residential hospice facilities, most hospice care takes place in the patient’s home or the home of a loved one, and less frequently in hospitals and nursing homes.

Hospice care is far less expensive than other types of end-of-life care (e.g., aggressive chemotherapy). Hospice patients are more often able to die at home (NHPCO, 2015).
SERVICES DELIVERED BY A HOSPICE MULTIDISCIPLINARY TEAM

- Manage the patient’s pain and symptoms
- Assist the patient with the emotional, psychosocial, and spiritual aspects of dying
- Provide needed drugs, medical supplies, and equipment
- Instruct the family on how to care for the patient
- Deliver special services like speech and physical therapy when needed
- Make short-term inpatient care available when pain or symptoms become too difficult to treat at home or the caregiver needs respite
- Provide bereavement care and counseling to surviving family and friends

Source: NHPCO, 2015.

An estimated 8 out of 10 nursing homes have arrangements to provide hospice care. However, nursing home staff and/or families must recognize the need for hospice care. Families should also be aware that long-term care facilities may have a financial incentive to continue skilled nursing care rather than switching to hospice care.

Hospice is not just for people with cancer. Any patient who is diagnosed with chronic illness may be eligible for hospice care. In fact, 63.4% of those admitted to hospice in 2014 had a noncancer diagnosis such as heart disease, kidney disease, liver disease, emphysema, non-ALS motor neuron disease, Alzheimer’s or other dementia, HIV/AIDS, or an unspecified debility. Participating in hospice care allows dying patients more time to spend with family and loved ones rather than focusing on medical care (NHPCO, 2015).

The Growing Range of Programs

As more Americans choose palliative care, the range of available options is expanding. The number of palliative care programs in hospitals is increasing rapidly. In addition, programs called open-access hospice, bridge hospice, or outpatient palliative care offer patients both comfort/supportive care in their home, nursing home, or assisted-living facility together with the opportunity to continue disease treatment, such as chemotherapy and radiation. Patients also have access to an interdisciplinary team of experts to address psychosocial and special care needs. The hope is that these new programs will encourage more patients and their families to enter hospice earlier and avoid the costly final weeks of hospitalization that so many Americans experience at the end of life (NHPCO, 2015).

Open-access programs are available to those without the ability to pay and are usually available through larger hospice facilities. Smaller agencies, various visiting nurse associations (VNAs), or home health agencies may provide a program of palliative care for terminal patients and their families that is not restricted by the expectation of expiration in six months or the requirement to
forego life-prolonging treatments. This kind of program “bridges” the period between hospitalization and aggressive treatment and hospice care at the end of life (VNA, 2013).

Palliative care and support services may be provided at any time during an illness, even from the time of diagnosis. It can take place at the same time as curative treatment. Hospice always provides palliative care; however, hospice is focused on patients who no longer seek treatments to cure them.

**Medicare Hospice Benefits**

Medicare, Medicaid (in most states), the Department of Veterans Affairs, most private insurance plans, HMOs, and other managed care organizations pay for hospice care. Community contributions, memorial donations, and gifts allow many hospices to give free services to patients who cannot afford payment. Some programs charge patients according to their ability to pay on a sliding scale (ACS, 2016).

According to the Patient Protection and Affordable Care Act of 2010, the majority of patients in hospice care are covered by Medicare. To qualify for the first 180 days of hospice care, the patient’s physician and the hospice medical director (also a physician) must see the patient and certify that the patient has less than six months to live if the disease runs its normal course. The hospice doctor or nurse practitioner must recertify the patient in a face-to-face visit before each benefit period after that. Medicare offers a one-time only hospice consultation with a hospice medical director or hospice doctor to discuss care options (ACS, 2016).

**HOSPICE CARE AND CURATIVE TREATMENTS**

Medicare beneficiaries are required to forgo curative care such as chemotherapy and radiation therapy in order to receive hospice services, although the patient may discontinue hospice services and return to more aggressive treatment at any time. This requirement is one reason some people avoid hospice until the last days or weeks of life and continue with aggressive, expensive treatment, which may make little or no difference in survival time and may diminish the quality of life in the process.

Through the Medicare Care Choices Model, however, 141 participating hospices offer hospice-like support services to patients who are also receiving curative treatments. Participation is limited to patients with advanced cancers, COPD, congestive heart failure, or HIV/AIDS. The duration of the model is three to five years. The Centers for Medicare & Medicaid Services will evaluate whether this model improves the quality of life, increases patient satisfaction, and reduces Medicare expenditures.

Source: ACS, 2016; CMS, 2016b.

Hospice agencies receive per diem payments that vary according to the site where services are received and any other insurance coverage the patient may have. In 2015, the per diem payment for routine home hospice care was $160 (Harrison & Connor, 2016). Payments are used to manage all care related to a patient. The benefits continue, provided that physicians certify that
the patient continues to meet the eligibility requirements. Medicare enforces an aggregate cap for agencies, effectively limiting the total amount they can receive (CMS, 2016a).

Hospice services covered by Medicare are listed below. In addition, many private healthcare plans and Medicaid cover hospice services.

**HOSPICE SERVICES COVERED BY MEDICARE**

Medicare covers these hospice services and pays nearly all of their costs:

- Physician services
- Nursing care
- Medical equipment (such as wheelchairs or walkers)
- Medical supplies (such as bandages and catheters)
- Drugs for symptom control and pain relief (patients may need to pay a small copayment)
- Short-term care in the hospital
- Short-term respite care (patients may need to pay a small copayment)
- Home health aide and homemaker services
- Physical and occupational therapy
- Speech therapy
- Social worker services
- Dietary counseling
- Bereavement services for patients and families (up to 13 months after a patient’s death)
- Any other covered Medicare services needed to manage pain and other symptoms, as recommended by the hospice team

All Medicare-certified hospices are required to employ physicians and nurses with special expertise in pain management and symptom relief. Nonpain symptoms include (but are not limited to) constipation, dyspnea, nausea and vomiting, dry eyes, and dry mouth. Bereavement and spiritual counselors are also available to help the dying and their families explore their needs and preferences as they come to terms with death.
LEGAL AND ETHICAL FACTORS IN END-OF-LIFE CARE

The Right to Die

The right-to-die movement in America is gaining public support, indicating widespread dissatisfaction with the quality of end-of-life care. The right-to-die concept includes assisted suicide (also called physician aid in dying [PAD]) and voluntary active euthanasia. In assisted suicide, the healthcare practitioner, usually a physician, provides the means to end life—such as a prescription for a lethal amount of drugs, the drugs themselves, or other measures—by a patient or a person who has knowledge of the patient’s intention.

According to the American Nurses Association (2015) Code of Ethics, Provision 1.4, however, nurses “may not act with the sole intent of ending a patient's life” even though such action may be motivated by compassion, respect for patient autonomy, and quality of life considerations.

Both nurses and physicians are confronted with requests for assistance in dying. However, this practice is legal in only five states. In 1994, Oregon became the first state to pass right-to-die laws. Montana and Washington soon followed (Hendry et al., 2013). In 2013, the Vermont legislature passed a right-to-die law in a close 75–65 vote. The guidelines for practice are very stringent. In 2015, California became the fifth state to pass a law allowing terminally ill patients the right to end their own lives by using a lethal dose of medications ordered by a physician and self-administered. Two physicians must attest to the patient as being terminal within six months and mentally capable of making the decision (California Legislative Information, 2015).

Healthcare practitioners acknowledge that there is an underground practice of assisted suicide in the United States. Some maintain that the principle of double effect is used to justify what is really assisted suicide. The principle of double effect states that the potential to hasten imminent death is acceptable if it is the unintended consequence of the primary intention to provide comfort and relieve suffering. For example, a terminal patient with severe difficulty breathing may be given large doses of narcotic to relieve suffering. As the breathing is eased by the narcotic, there may be a second effect that stops breathing altogether.

Palliative Sedation Therapy (PST)

Palliative sedation therapy is considered a last-ditch option in end-of-life care to relieve terminal suffering. The suffering may be physical, psychological, or existential (a loss or interruption of meaning, purpose, or hope in life). PST may be used to treat intractable pain and suffering when other measures such as a physician-assisted death is not an option. Narcotic pain medications mixed with sedation for comfort and anti-anxiety medications may have the sometimes unintentional result of terminally sedating the patient (O’Rourke & Navarro-Leahy, 2016).

Palliative sedation therapy is controversial. Some opponents have incorrectly equated it with euthanasia. Euthanasia and PST are different in intention (relief of intolerable suffering in PST, killing the patient in euthanasia), in procedure (use of a sedative for symptom control in PST, use
of a lethal agent in euthanasia), and in outcome (alleviation of suffering in PST, immediate death in euthanasia) (Dwyer & McCarthy, 2016).

As pain escalates and becomes more difficult to control, it may be necessary to consider palliative sedation. Palliative sedation is an appropriate method to consider when symptoms are refractory (not adequately controlled with conventional treatment options). Poorly controlled pain, agitation, refractory dyspnea, vomiting, and extreme psychological or existential suffering about impending death are the primary reasons for using palliative sedation (Azoulay et al., 2016).

### EUROPEAN ASSOCIATION OF PALLIATIVE CARE 10-ITEM FRAMEWORK FOR GUIDELINES IN PALLIATIVE SEDATION

1. Recommend preemptive discussion of potential role of sedation in end-of-life care and contingency planning.
2. Describe the indications in which sedation may or should be considered.
3. Describe the necessary evaluation and consultation procedures.
4. Specify consent requirements.
5. Indicate the need to discuss the decision-making process with the patient’s family.
6. Present direction for selection of the sedation method.
7. Present direction for dose titration, patient monitoring, and care.
8. Guidance for decisions regarding hydration and nutrition and concomitant medications.
9. The care and informational needs of the patient’s family.
10. Care for the medical professionals.


The role of the nurse in palliative sedation includes the administration of medications, recognizing and notifying healthcare practitioners of refractory symptoms, providing psychosocial support and education to the patient and family, and identifying culturally specific needs related to dying and death. Nurses have a responsibility to provide symptom relief and prevent suffering in dying patients (ANA, 2015). It is important to palliative nurses that consent by the patient or family be given before administering potentially lethal doses of sedation to the terminally ill (Dwyer & McCarthy, 2016).

### TYPES OF PST

Two types of palliative sedation may be used in end-of-life care: **proportionate palliative sedation** (PPS) and **palliative sedation to unconsciousness** (PSU). In PPS, medications such as benzodiazepines are increased gradually together with other symptom-relieving measures until
suffering is relieved during both waking and sleeping hours. In a study of 179 patients who died during 2012, PPS was used among 21.2%. The medications used by the study participants were midazolam (Versed), haloperidol (Haldol), and concurrent morphine. Indications included agitation (71%), pain (36.8%), and dyspnea (21%). Survival following PPS was longest with higher sedative doses, an observation that may help dispel fears concerning the use of PPS to hasten death (Azoulay et al., 2016).

In PSU, unconsciousness is the intended goal of sedation rather than a side effect. Medications are increased rapidly over minutes and hours to achieve unconsciousness and left at that level until death occurs. PSU is usually administered when the imminently dying patient finds severe physical symptoms intolerable despite state-of-the-art palliative care.

However, controversy surrounds the use of PSU to treat psychological, existential (a loss or interruption of meaning, purpose, or hope in life), or spiritual suffering. Some consider these to be outside the realm of a physician’s expertise, and others consider them within the knowledge, tools, and expertise of the interdisciplinary team.

Health professionals need to understand the difference between the practice of PPS and PSU and the ethical issues surrounding their use. Nurses understand that the timing and appropriateness of palliative sedation is crucial to the patient or family’s comprehension and consent. Patients and families need to understand these last-resort options and make decisions about such end-of-life care before the need arises (Dwyer & McCarthy, 2016).

Healthcare practitioners also need to recognize that the patient always has the right to stop unwanted medical treatments or procedures while they are in progress—as was the case prior to consenting. These procedures may include CPR, mechanical ventilation, and artificial nutrition and hydration.

**CASE**

Doris is in the terminal phase of stage IV pancreatic cancer and experiencing severe abdominal pain much of the time. She has been under hospice care and requires proportionate palliative sedation (PPS) to achieve any degree of relief from the pain. It is Doris’s expressed wish that she not be left in intractable pain, and she has named her daughter Sheila in her advance directive to make medical decisions if she is unable. Sheila has been estranged from her mother for seven years but is now at her side most of the time.

The PPS has left Doris comfortable, rousable, but barely coherent. When her mother is unable to answer questions, Sheila asks that the PPS be reduced, stating her mother would want to be able to communicate with family. When the PPS is withdrawn, Doris becomes more lucid but complains of severe abdominal pain and asks for more pain medication. This results in periods of unresponsiveness, causing Sheila to again instruct the nurses to decrease the medication.

Donna is the charge nurse on Doris’s unit and has 20-plus years of experience in oncology. She arranges a conference for the following day with the family, including Sheila, the palliative care nurse, the primary physician, and Donna herself. Sheila is encouraged to express her fears of losing her mother and her hope to have time to communicate with her first. The group
discusses the severe level of pain caused by pancreatic cancer and Doris’s wish that she not experience intractable pain. A compromise is reached that takes both Doris’s and Sheila’s wishes into consideration.

## Removing or Deactivating Cardiovascular Implants

Implanted cardioverter/defibrillators (ICD) are used to correct life-threatening dysrhythmias. An actively dying patient may develop ventricular tachycardia due to hypoxia or electrolyte imbalances. If the ICD has not been deactivated or reprogrammed to prevent shocks, the device will continue to attempt to function by delivering painful shocks.

A consensus statement from the Heart Rhythm Society (2010) suggests that patients nearing the end of life (or their healthcare proxy) have the right to decide whether to have these pacemakers or other cardiovascular implants removed or deactivated. The statement was developed in collaboration with several organizations, including the American College of Cardiology and the American Heart Association. It explicitly states that removing or deactivating an implanted cardiovascular device near the end of life “is not physician-assisted suicide or euthanasia.” However, it also states that physicians or other caregivers cannot be compelled to carry out a procedure that conflicts with their ethical values. In such cases, the physician cannot abandon the patient but rather should refer patients to a colleague willing to carry out the task (Thanavaro, 2012).

## Advance Directives

Advance medical directives are documents containing patients’ oral and written expressions of their preferences about future medical care if they should become unable to speak for themselves. Federal law (the Patient Self-Determination Act) requires hospitals to inform patients that they have the right to complete an advance directive.

Less than one third of Americans have advance directives (i.e., a living will and a healthcare power of attorney). Older patients are more likely to have such directives, with 41.2% self-reporting them in a recent study (Waite et al., 2013).

When a surrogate is making end-of-life decisions for a patient, the surrogate will be expressing the wishes of the patient that they have previously discussed. Particularly in the case of chronic illness where a slow physical or mental decline takes place, advance directives provide the opportunity to ensure that a person’s own preferences will be followed. Copies of the advance directive may be given to family, care providers, one’s hospital, an attorney, or others. The plan should be reviewed periodically to provide for necessary updates (CDC, 2014).

Healthcare professionals have an obligation to work with patients and their families to reach decisions that balance autonomy and beneficence.
LIVING WILL AND MEDICAL POWER OF ATTORNEY

In most states, an advance directive can be either a living will or a medical power of attorney, also called a durable power of attorney for healthcare, a healthcare proxy, or declaration or appointment of a healthcare agent. Advance directives are regulated by state law and therefore may differ from state to state.

A living will is a document one can write while alive to dictate preferences for healthcare decisions. A medical or durable power of attorney names one or more people who may make decisions for the person who is unable to make their wishes known (CDC, 2014). A healthcare proxy is the person who is named as the decision maker and may have his or her name listed in the advance directive form.

According to the President’s Council on Bioethics (2005), “advance instruction directives (or living wills), though valuable to some degree and in some circumstances, are a limited and flawed instrument for addressing most of the decisions caregivers must make for those entrusted to their care.” Rather than try to anticipate every aspect of future circumstances, the Council found that,

Advance proxy directives are much more valuable and should be encouraged. . . . Naming of proxy decision makers provides clear identification of who shoulders the responsibility to act for the patient and makes it clear to physicians and others with whom they must deal. Such knowledge makes it much more likely that there will be the desirable discussions between family and professional caregivers at all important junctures of treatment and care.

PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST)

Several states have adopted an advance directive form developed in Oregon and known as POLST, which stands for Physician Orders for Life-Sustaining Treatment (POLST, 2016). This simple form, to be completed and signed by both patient and a physician or nurse practitioner, specifies the patient’s preferences concerning measures such as antibiotics, artificial nutrition (including tube feeding) and hydration, CPR, comfort measures, and mechanical ventilation/respiration.

The form is printed on brightly colored paper and stays with the patient during transfers from one care setting to another. Patients at home keep the POLST form on the refrigerator, where emergency responders can find it. Long-term care facilities retain POLST forms in residents’ charts. (See “Resources” at the end of this course for information about POLST programs in each state.)

DO-NOT-ATTEMPT-RESUSCITATION (DNAR) ORDERS

Do-not-attempt-resuscitation orders (formerly known as do-not-resuscitate orders) have been renamed to emphasize the minimal likelihood of successful cardiopulmonary resuscitation
(CPR). Additionally, a specific order to refrain from intubation is referred to as “do not intubate” (DNI).

Patients and families need to understand not only the unlikely success of resuscitation but also the risks involved, which include fractured ribs, damaged internal organs, and neurologic impairment. Although the patient (or family) must ultimately decide about whether to attempt CPR, healthcare professionals need to explain that withholding CPR does not equate with letting someone die. Rather, a DNAR order should be considered an “allow natural death” (AND) order (Curesearch, 2016).

The primary care provider should discuss the possibility of a DNAR order as soon as it is reasonable. A delay in putting a DNAR order in place may result in treatment unwanted by the patient and distress for the healthcare team. The DNAR order should be readily available in the event of an emergency to ensure that the patient’s wishes will be honored. It should be posted prominently, either on the head or foot of the bed, or if the patient is at home, on the refrigerator. The specifics of the order should also be carefully documented in the patient’s chart (University of Illinois at Chicago, 2013).

**MECHANICAL VENTILATION (MV)**

Decisions about mechanical ventilation can be spelled out in the patient’s advance directive. Some patients choose to forgo MV, believing that it merely prolongs the dying process. Others choose to have MV when they can no longer breathe on their own. Choosing MV may reflect the erroneous belief that this life-sustaining treatment can improve the patient’s prognosis.

Depending on the physician, choosing MV may affect the physician’s certification of the patient as terminal and, therefore, the patient’s eligibility for hospice benefits. Use of MV requires that the patient lie in bed or sit in a chair with restricted movement. If an endotracheal tube is used, the patient will not be able to speak or swallow. Mechanical ventilation also increases the risk of pneumonia because it prevents patients from coughing effectively and allows fluid to build up in the lungs.

Once MV is started, the decision to withdraw it may present a legal and ethical controversy for the physician and the family. In some cases, withdrawal of this life support may require a court order.

**ARTIFICIAL NUTRITION AND HYDRATION (ANH)**

Patients who receive hospice care have food and drink as they wish or need. Some individuals make their own choice (often as part of an advance directive) to stop or limit eating or drinking at a certain point in their dying process. When oral nutrition is no longer safe for a patient, ANH using enteral feeding tubes is sometimes used to deliver nutrition (Arenella, 2014).

Decisions about whether to have ANH involve weighing the potential benefit and the burden to the patient. Clinicians need to help families understand that forgoing ANH is not “killing” or “starving” the patient. The most recent American Nurses Association (ANA) position statement
shows there is consensus in the nursing profession regarding ANH. The ANA supports a patient’s (or surrogate’s) right to weigh the risks and benefits of ANH after a full discussion by the healthcare team (ANA, 2011). The ANA position statement supports the ANA beliefs about autonomy, relief of suffering, and patients receiving expert care at the end of life.

Little evidence supports the use or disuse of hydration as a comfort measure in end of life. The reason for this lack of evidence is that it is not ethically possible to conduct a controlled, randomized clinical trial in which one group of patients near the end of life receives hydration and a second group has hydration withheld (AAHPM, 2013).

Although ANH may extend the patient’s life a few days or weeks, there is considerable physical and emotional trauma in inserting a nasogastric tube or undergoing surgery to place a gastrostomy (feeding) tube. There is also the increased risk of infection, increased risk of aspiration, erosion of nasal tissue, and increased diarrhea, all of which would prolong suffering.

Application of restraints to keep the patient from pulling out the tube can cause the patient to struggle. Nasogastric tube feedings can lead to such complications as pain, aspiration pneumonia, epistaxis, pharyngitis, esophagitis, airway obstruction, and metabolic derangements. Many health professionals feel that hospice care with cessation of feeding and fluids is a more humane alternative to ANH (AAHPM, 2013).

There is widespread use of feeding tubes at the end of life, particularly in patients with Alzheimer’s disease or other cognitive impairment, even though there is not sufficient evidence to prove enteral tube feeding is beneficial in patients with advanced dementia. (See also “The Patient Who Has Dementia” below.)

Research suggests that people who choose not to have ANH do not suffer due to hunger or thirst. Furthermore, without ANH, patients are less likely to experience bloating or to develop pleural effusions (fluid around the lungs), which can cause shortness of breath, or fluid in the throat, which requires suctioning. Studies also indicate that forgoing artificial hydration increases the body’s production of endorphins (natural pain-relieving hormones), making the patient more comfortable and less likely to experience pain. The only side effect of dehydration at the end of life is dry mouth, which can be relieved by good mouth care, ice chips, or moistened sponge swabs ( Arenella, 2014).

**CASE**

Kathy, a hospice RN, was questioned by the family of an elderly patient on hospice care in the nursing home where she worked. When the discussion turned to a decision about continuing artificial nutrition and hydration (ANH) for their loved one, a few of the family members expressed concern that withholding nourishment and liquids would cause unnecessary suffering by “starving her to death.” Kathy was able to explain that studies have shown no benefit in giving tube feedings or intravenous (IV) therapy to dying patients, and in fact could possibly cause discomfort or pain. Kathy assured the family that the nursing staff would continue to keep the patient comfortable, give her pain medication when needed, and moisten her mouth with ice chips to keep it from feeling dry.
EFFECTIVE COMMUNICATION WITH PATIENTS AND FAMILIES

Although talking about illness and death can be difficult for both health professionals and patients, studies show that most patients want to have this discussion. Sharing bad news while maintaining hope is a delicate balance that takes practice to achieve. Health professionals need to support the patient’s and the family’s hopes for prolonging life as well as their hopes for peace and dignity throughout illness, dying, and death. While uncomfortable, conversations about many aspects of end-of-life care are crucial. Effective management of pain and other symptoms as well as emotional and psychological support of the patient and family are always possible.

Effective communication by hospice nurses and all of the members of the multidisciplinary team enhances symptom management for the patient, reduces family caregiver burnout and distress, and potentially improves bereavement adjustment (Bhatt & Mitchell, 2015).

STRATEGIES FOR PROMOTING FAMILY-CENTERED END-OF-LIFE CARE

- Get to know the family.
- Assess the family's understanding of the patient's condition.
- Keep the family informed.
- Provide clear, honest information to the family.
- Maintain consistency of care providers.
- Coordinate early family meetings.
- Facilitate the decision-making process.
- Assist the family through shared decision-making.
- Guide the family through the end-of-life process.
- Prepare the family for what to expect during the dying process.

Source: Wiegand et al., 2013.

When and How to Talk about Death

A pilot study by Ellington and colleagues (2012) explored home health hospice nurse communication with caregivers and patients with cancer. Patient-centered communication has been proven to be directly linked to improved patient outcomes such as a reduction in stress. The hospice nurses ask open- and closed-ended questions that attempt to persuade, suggest, or change behavior within all topic domains:

- Physical care
- Psychosocial
- Lifestyle
Many patients need permission or an invitation to express their values and preferences about end-of-life care. One way to broach the subject is with an open-ended question such as, “When you think about getting very sick, what worries you the most?” “How important is your religion to you?” “You sound very frustrated with your family.” “I am really worried that you aren’t getting enough sleep.”

Some questions or statements are directed to the caregiver: “You need to make the effort to take a break every day” or “I was very close with my mother, too.”

Another way to open the conversation is to say: “Many patients with this condition tell me they think about dying. They have questions about this. How about you?” “What do you think would help?” “How do you think you could tell your kids about this?” Making empathic statements gives the patient an opportunity to express needs and concerns and shows the healthcare practitioner’s concern for the patient. Feeling that one’s doctor or nurse truly cares evokes trust, confidence, and hope in the patient.

Raising the topic of advance directives can also help to open the discussion of what the patient wants, needs, expects, and fears during this final phase of life. The following questions may be helpful:

- If you were to get so sick that you could not talk to me directly, whom should I talk with to help me make decisions about your care?
- Does this person know about this responsibility?
- Does he or she know what you want?
- What would you want?
- Have you written down what you want?

The physician is most likely to initiate the conversation, but nurses and other healthcare practitioners should also be prepared to discuss these issues as needs and circumstances change.

Actively listening to the patient is equally if not more important than talking to the patient. Questions that will elicit key information about the patient’s perspective include:

- What do you hope for as you live with this condition?
- What do you fear?
- It is usually hard to know when death is close. If you were to die soon, what would be left undone in your life?
- How are things going for you and your family?

Both patient and family need timely, clear information about prognosis. It is difficult, and often impossible, for clinicians to answer questions about “how long,” but it is possible to describe the probable course of a particular illness in understandable terms. This helps patients do what is
Most important to them, such as making a will, seeing family and friends, and telling loved ones. Clinicians tend to be overly optimistic when discussing prognosis, which can delay referral to hospice and cause unnecessary pain and suffering for the patient and family.

Explicitly discussing death helps the patient express fears and concerns about the dying process and allows the clinician to address them directly. For example, the patient may say, “I don’t want to die hooked up to machines” or “I don’t want any heroics.” This is an opportunity to allay that concern, for instance, by talking about hospice care and to ascertain whether the patient has an advance directive in place or would like information about one.

### FAMILY CONFERENCES FOR PATIENTS DYING IN THE ICU

End-of-life family conferences are an important part of intensive care unit (ICU) practice in many hospitals because they help relieve stress and anxiety for those with loved ones dying in the ICU. Families are intricately involved in the end-of-life decision-making process for a family member with a serious illness who is in the ICU setting. However, families are not always as involved and as informed as they would like to be.

Ideally, these conferences are held in a quiet room once the family has been given sufficient time to gather. They allow for discussion of the patient’s situation and an opportunity for the family to ask questions, express concerns, and confront painful emotions with the help of caring, compassionate professionals. Included in these discussions will be the attending physician, the nurse most familiar with the patient, and possibly a member of the clergy.

Guidelines for these conferences are based on the VALUE mnemonic:

<table>
<thead>
<tr>
<th>VALUE</th>
</tr>
</thead>
<tbody>
<tr>
<td>V</td>
</tr>
<tr>
<td>A</td>
</tr>
<tr>
<td>L</td>
</tr>
<tr>
<td>U</td>
</tr>
<tr>
<td>E</td>
</tr>
</tbody>
</table>

Source: Wiegand et al., 2013.

### Cultural Sensitivity

Culture is often defined as the set of attitudes, beliefs, and values that people and societies pass down between generations. It can have a significant impact on patients’ and families’ beliefs and expectations in the healthcare setting. Cultural sensitivity also includes the avoidance of stereotyping.
Diversity of values and beliefs exists within each culture, making it important to ask open-ended questions rather than making assumptions based on appearances. Cultural beliefs about healthcare, especially end-of-life issues, are as diverse as the different cultures that seek healthcare. Cultural competency requires that healthcare workers understand these differences to be effective and respectful in their delivered care.

“BENEFICENCE” VERSUS “TRUTH-TELLING”

Whereas the mainstream U.S. model of end-of-life care values autonomy and “truth-telling,” healthcare models in other cultures value beneficence, which includes protecting the patient from bad news about serious illness. In these cultures, disclosure of serious illness may be considered disrespectful, impolite, or even harmful to the patient.

Learning about the patient’s and family’s cultural values can begin with a simple statement followed by an open-ended question: “Some people want to know about their illness and others do not. Some would prefer that I talk with a family member. How do you feel about it?” This gives the patient the option to refuse or accept information about diagnosis or prognosis and to designate a family member to act as a surrogate.

Researchers suggest three strategies for addressing the “secrecy” dilemma and other cultural differences in end-of-life care:

- Community education to increase the knowledge about palliative and hospice care
- Use of case assessment tools to determine communication preferences and the family’s role in decision-making
- Providing culturally sensitive end-of-life navigation

In Latino communities, promotores may prove helpful in implementing the above education and communication strategies. Promotores are community members who promote health in their own communities and help to alleviate barriers to access to care. As members of minority and underserved populations, they are in a unique position to build on strengths and to address unmet health needs in their communities (Rhett-Mariscal, 2016).

Some cultures emphasize family versus individuals (collectivism) and family decision-making (CHCF, 2014). Protecting the patient from bad news means that decisions about care will be made by the family, the physician, or a family/physician collaboration.

DIVERSE PREFERENCES

Preferences about end-of-life care are as diverse as America’s population. In communicating with patients and families about end-of-life care, it is important to be aware of different cultural attitudes and practices. For instance, completing advance directives is less common among Asian Americans, Hispanic Americans, and African Americans. Likewise, there are well-documented
differences in preferences for end-of-life care and the use of services between non-Hispanic whites and African Americans.

African Americans do not use advance care planning documents or hospice as much as non-Hispanic whites. African Americans choose more aggressive, life-sustaining treatment at the end of life, even if that treatment seems likely to be burdensome with little chance of success. The reasons for this are multifaceted and include knowledge of and access to services, historical mistrust of the healthcare system, and spiritual beliefs. To many African Americans a good death includes prayer, Bible reading, spiritual counseling, and singing religious hymns (Becze, 2013). Hospice services may be seen as unnecessarily intrusive upon the patient’s and family’s grieving process.

Hispanics are often very concerned about dying with dignity and receptive to hospice care and hospitals, but they may want to avoid nursing homes. The majority of older Hispanic patients prefer less aggressive comfort care at the end of life. The initiation of advance directives by Hispanic patients is very low in spite of the provision of bilingual and culturally sensitive information. The majority of Hispanics have never discussed advance care planning with their physicians. Older Latinos are less likely to use hospice services and more likely to die in the hospital than non-Hispanic whites (Fernandez, 2013).

Among Asian Americans, the preference for advance directives included asking for relatives’ advice, wishing to be informed of their terminal illness diagnoses, absence of stroke, and having no problems with self-care. In one study, most cognitively normal Asian older adults in nursing homes preferred having an advance directive, and one third of them preferred to die in nursing homes (CHCF, 2014).

**MANAGEMENT OF PAIN AND OTHER SYMPTOMS**

Pain is now recognized as the fifth vital sign. Many people who have come to terms with their own mortality still fear the possibility of a painful death, and that fear is justified. Eighty percent of patients with advanced cancer experience severe pain. Patients with other chronic diseases such as AIDS, sickle cell disease, and arthritis also suffer extreme pain, which may be ineffectively treated. Experts estimate that, when properly treated, almost all of these patients could gain significant relief from pain (Lewis et al., 2014).

Inadequately treated pain has many potential consequences, including reduced quality of life, reduced function, physical complications, reduced ability to tolerate treatments, and psychosocial difficulties. Almost all pain can be controlled to some extent with the wide range of available treatments.

The patient’s preferences should define the goal of pain management. Some patients will choose to be completely pain-free, even if it means sedation. Others will choose only to control pain enough so that they can continue to function with alertness. If pain becomes severe at any time, but particularly in the last days or hours of life, it should be treated around-the-clock.
Pain is frequently multidimensional, with psychosocial and spiritual components. Other symptoms, distress, or psychosocial or spiritual concerns can interact with and exacerbate physical pain or impact the effectiveness of pain treatment (Lewis et al., 2014). Pain not only hurts, but it is also physically and emotionally debilitating. Severe chronic pain can cause depression, anxiety, fear, diminished appetite, impaired sleep, irritability, inability to focus, and sometimes thoughts of suicide. When pain is relieved, many of these symptoms disappear. The patient then can focus on other important end-of-life issues, such as unfinished business with family and friends or spiritual or religious concerns.

**Patients have a right to relief from pain.** The Joint Commission requires that hospitals and other healthcare facilities regularly assess, monitor, manage, and document pain and response to treatments in all patients. Those facilities that fail to do so risk losing accreditation. Until all health professionals learn the principles of pain management explicit to palliative care, however, patients will continue to suffer needlessly.

Inadequate education of health professionals in pain management is only one reason why patients suffer. The other is general mistrust about the use of narcotic analgesics and worry about addiction or overdosing on these medications. Patients may also consider requests for pain medication as “giving up” or “giving in” to their disease. Clinicians can correct these myths and misinformation and reassure patients that managing their pain is fundamental to improving their quality of life.

Although addiction is not a concern when treating dying patients, tolerance to and a chemical dependence on opioids may develop over time. If tolerance to particular drugs occurs, it will be necessary to increase the dosage or change medications to gain relief. If dependence develops and the patient needs to be taken off the drug, it should be done gradually in order to avoid withdrawal symptoms.

**Assessing Pain**

Effective pain management begins with assessment of the patient’s pain. Because pain is a subjective experience, it is important to ask the patient to describe the pain in terms of location, intensity, and character. There are a number of pain assessment tools available; healthcare practitioners should consult their agency protocols.

Pain perception varies from person to person, depending on age, culture, emotional status, past experiences with pain, and the source and meaning of the pain. Some cultures dictate stoicism when experiencing pain, which may cause people not to admit pain or request medication. Men are more likely to “tough it out” because of cultural and gender attitudes.

Older adults may have a higher pain threshold than younger people or children due to normal age-related changes in neurophysiology. Because of their higher pain threshold, however, older patients are at risk for undertreatment of pain. They may have multiple chronic diseases and sources of pain as well as complex medication regimens that increase the risk of drug-drug and drug-disease interactions.
Visual, hearing, motor, and cognitive impairments as well as language differences can impede communication about patients’ pain. Anxiety and depression can exacerbate the pain experience, as can fatigue and sleeplessness. Untreated pain can then cause further sleeplessness, which leads to more fatigue, setting up a cycle of suffering.

Knowing the source of pain can be a relief in itself, particularly if the patient has imagined a worst-case scenario and the source of the pain turns out to be a minor, correctable condition. The meaning of pain also affects the patient’s perception of it.

Pain should be reassessed at least as often as the vital signs are taken and management efficacy reassessed when patients are transferred from home to any new healthcare facility (Lewis et al., 2014).

**Pain Medications**

Medications can make a drastic difference in the lives of those suffering with pain, and they comprise an important aspect to end-of-life care in many instances. (A detailed description of pain medications is beyond the scope of this course, but the following provides basic information.)

**THREE-STEP LADDER APPROACH**

The World Health Organization has developed a three-step ladder approach to pain management (see diagram below).

![WHO three-step dosing model for the treatment of pain.](Source: Adapted by author from WHO, 2013.)

Using this guideline for managing pain does not mandate sequential use, particularly in terminal illness. Patients with severe pain may need to begin with step 3. To maintain freedom from pain, drugs should be given “around the clock,” that is, every 3 to 6 hours rather than “on demand or
PRN.” This three-step approach of administering the right drug in the right dose at the right time is inexpensive and 80% to 90% effective.

**Step 1 analgesics** include aspirin, acetaminophen, and nonsteroidal anti-inflammatory drugs (NSAIDs). Types of NSAIDs include ibuprofen, aspirin, naproxen, ketorolac, and diclofenac (NSAIDslist.com, 2013). All pain medications, even step 1 analgesics, have side effects. NSAIDs can cause gastrointestinal bleeding. Acetaminophen can be toxic at doses exceeding 4 grams in 24 hours, particularly in patients with compromised liver function.

**Step 2 and step 3 analgesics** include the opioids, such as codeine, fentanyl, hydrocodone, hydromorphone, morphine, and oxycodone. In step 2, the opioid is combined with either acetaminophen or aspirin. In step 3, the opioid and a step-1 drug are combined with adjuvant drugs such as antidepressants (e.g., fluoxetine, sertraline, and escitalopram) (WHO, 2013).

**DRUG ADMINISTRATION**

Many opioids are available in sustained-release form as tablets and granules. Fentanyl is also available in a skin patch that will last up to 72 hours. However, sustained-release formulations should not be used for “rescue” dosing because they will not work quickly enough to relieve intense pain. In January 2010, the FDA approved morphine sulfate oral solution for the relief of moderate-to-severe acute and chronic pain in opioid-tolerant patients. Each 5 mL contains 10 mg or 20 mg of morphine sulfate (Daily Med, 2016).

When a patient is unable to swallow an oral medication, less invasive routes (rectal, sublingual, or transdermal) should be offered first. Parenteral methods should be used only when simpler, less-demanding, and less-costly methods are inappropriate, ineffective, or unacceptable to the patient. Intravenous (IV) or subcutaneous doses should be chosen over intramuscular (IM) injections, as they are less painful and absorb at a comparable rate. In general, assessing the patient’s response to several different oral opioids is advisable before abandoning the oral route in favor of anesthetic, neurosurgical, or other invasive approaches (Lewis et al., 2014).

Oral transmucosal fentanyl citrate is used for the relief of breakthrough pain. The lipid solubility of fentanyl allows rapid onset of pain relief. Fentanyl can also be given in the form of an intranasal spray, topical skin patch, or a buccal tablet for patients who are unable to swallow pills.

End-of-life patients may experience agitation. Lorazepam (Ativan) is an anxiolytic/sedative that may be taken as an injection, intravenously, orally, or sublingually (Healthcentral.com, 2013).

**PROPER SAFEGUARDING OF NARCOTICS**

Many end-of-life patients receiving palliative care or hospice at home possess large amounts of narcotics and other controlled substances to alleviate pain and control anxiety. While these are essential to keep the patient comfortable, abuse and disposal of such medications may pose problems. Improper disposal of these substances by flushing down the toilet or into sinks may
introduce them into the groundwater and drinking water supplies, and they have been measured in the tissue of aquatic organisms (Mankes & Silver, 2013).

Instead, unused drugs may be given to collectors who are registered with the Drug Enforcement Administration. Authorized collection sites may be retail pharmacies, hospitals, clinic pharmacies, and law enforcement locations. Some may offer mail-back programs or collection receptacles (“drop-boxes”).

Equally important is the need to safeguard against the use of controlled substances in the home by anyone other than the patient for whom the medications were ordered, including children and pets (FDA, 2016).

**CASE**

Isabella Delaney is a 76-year-old widow with an inoperable astrocytoma in the parietal lobe of her brain. She has undergone palliative radiation treatments in the hospital and has been discharged to home to be cared for by her 54-year-old daughter, Eileen, and a home health aide who comes every other day.

Although the tumor has shrunk in size since the radiation therapy, Isabella still complains of severe headaches, up to 7 or 8 on the 0–10 pain scale. Her doctor has ordered ibuprofen with fentanyl patches for the pain. Isabella is instructed to keep a log indicating when patches are applied and removed and how disposal of used patches is managed. Isabella is forgetful and occasionally neglects to remove the previous patch when she puts on the new one, every 72 hours. When this happens, she becomes confused, agitated, and even more forgetful. Also, she does not consistently maintain the log.

Eileen’s 28-year-old son, Paul, has a history of substance abuse and has been in rehab twice for narcotic addiction. Lately he has been taking his grandmother’s fentanyl patches when he visits his mother, telling himself they’re not good for Isabella. The home health aide notes that the count is off and notifies Eileen. She also notifies her agency supervisor. After reviewing all the circumstances (Isabella’s forgetfulness, the incomplete log, the presence in the house of a person with a known history of substance abuse), the supervisor instructs Eileen to lock up the supply of patches, remove and apply them herself to prevent overdosing, and lock up the used patches as well.

**ADDRESSING SIDE EFFECTS**

The use of opioids affords effective pain relief to most patients. Like all drugs, however, they have side effects, some of which can be uncomfortable or even painful in themselves. They include drowsiness, nausea and vomiting, dyspnea, dry mouth, and constipation. Some side effects ameliorate after a few days, and most can be prevented or treated successfully.
**Drowsiness**

Drowsiness frequently occurs at the beginning of opioid therapy, not only from drug action on the brain but also because the patient has been sleep-deprived due to unrelieved pain. Once normal sleep patterns resume, the drowsiness generally lessens.

**Nausea and Vomiting**

Nausea and vomiting can usually be controlled once the source of the problem is identified. For patients who cannot tolerate morphine or NSAIDs, substitution of a different opioid or a sustained-release formulation may relieve the symptoms. Vomiting related to chemotherapy can be treated with serotonin receptor antagonists such as ondansetron, granisetron, or dolasetron.

If nausea and vomiting are related to disturbances of the labyrinth—such as motion sickness, vertigo, or migraine—use of antihistamines and anticholinergics (meclizine, dimenhydrinate, or transdermal scopolamine) may offer relief.

In some patients, nausea and vomiting can be triggered by smells, sights, or sounds; this is referred to as psychogenic or anticipatory vomiting. For these patients, benzodiazepines (anti-anxiety drugs such as lorazepam and buspar of the azapirone chemical class) may provide relief. Benzodiazepines can interfere with short-term memory, especially in older patients, or cause confusion in those already cognitively impaired.

Vomiting may also be related to increased intracranial pressure (e.g., from central nervous system tumors). These patients may benefit from a combination of corticosteroids and serotonin receptor antagonists.

Constipation may trigger nausea and vomiting in patients with advanced disease. Stimulant laxatives such as senna derivatives can promote gut emptying and offer relief.

**Dyspnea**

Dyspnea (shortness of breath, difficult breathing) is common among dying patients, who may report a feeling of tightness in the chest or a feeling of suffocation. Dyspnea may be an initial effect of opioid therapy or may result from other causes, including pneumonia, pulmonary embolism, pleural effusion, bronchospasm, tracheal obstruction, neuromuscular disease, restricted movement of the chest or abdominal walls, cardiac ischemia, congestive heart failure, superior vena cava syndrome, or severe anemia. Treatment is determined by the diagnosis.

Three basic approaches are used to treat dyspnea in the dying patient: oxygen, opioids, and anti-anxiety medications. Nonpharmacologic methods such as meditation or guided imagery may also be effective. Although most patients are not hypoxic, supplemental oxygen may be helpful unless the cannula or face mask cannot be tolerated. Fresh
outdoor air or a breeze from a fan may also afford relief. Low-dose immediate-release morphine, in either oral or buccal formulations, also can be effective.

**Constipation**

Preventive measures against constipation should begin at the same time as opioid therapy. Normal bowel function varies from person to person, so it is essential to establish what the patient considers normal and whether he or she is having any difficulty with bowel movements. Preventive or treatment measures can then be tailored accordingly. Untreated constipation can cause bloating, abdominal pain, nausea and vomiting, overflow incontinence, fecal impaction, or bowel obstruction.

First-line therapy for constipation includes stool softeners and stimulant laxatives such as prune juice or senna derivatives. If these prove insufficient to maintain or restore normal bowel function, osmotic laxatives such as magnesium salts, sorbitol, or lactulose may be added.

A lubricant stimulant such as mineral oil may be used if the patient is able to swallow. However, mineral oil should not be given to patients who have difficulty swallowing because aspirating mineral oil can cause pneumonia. Mixing the oil with orange juice or root beer makes it more palatable. It should be given when the patient’s stomach is empty to avoid interference with fat-soluble vitamins.

If the patient is ambulatory, increased activity can help promote bowel function. Simple measures such as increased fluid intake, more dietary fiber (if tolerated), a regular toileting schedule, privacy, and if the patient is bedfast, use of a bedside commode rather than a bedpan can be helpful. Peristalsis is generally strongest after eating, especially in the early morning.

**Dry Mouth**

Pain medications and many other pharmaceuticals (e.g., antidepressants, anticholinergics) can dry the lips and oral mucous membranes, leading to cracking, ulceration, and bleeding. Patients on oxygen therapy and those who have chosen to forgo artificial hydration and nutrition may also experience dry mouth. When increasing fluid intake is not an option, lubricants such as liquid vitamin E or Blistex applied to the lips can help prevent cracking. Mouth swabs moistened with water or alcohol-free mouthwash can be used to relieve discomfort and to clean teeth, gums, and tongue. Limit or avoid use of any products containing alcohol, which can further dry the mouth.
TREATING OTHER END-OF-LIFE SYMPTOMS

Delirium

Delirium is a condition marked by changes in clinical and mental status and has been understood as prevalent and dangerous, particularly among elderly or frail patients. It is the most common neuropsychiatric disorder at the end of life. It is defined as a disorder of global cerebral dysfunction characterized by disordered awareness, attention, and cognition (Hosker & Bennett, 2016).

Disturbances in sleep-wake cycles and psychomotor activity, delusions or hallucinations, insomnia, and emotional lability may all occur. The agitation, moaning, and grimacing of delirium may be misinterpreted as signs of pain. The person may also exhibit mood swings, disorientation to time and place, and uncharacteristic speech. The most significant elements of dementia are inattention and broad fluctuations of symptoms. These are not major components of any other psychiatric illness of late life (Hosker & Bennett, 2016).

Delirium can create distress for both patient and caregivers, interfering with patient comfort and meaningful interaction with family members.

Many episodes of delirium can be effectively treated and in some cases prevented. Delayed treatment may result in terminal restlessness. Risk factors for delirium include cognitive impairment, sleep deprivation, medications such as narcotics or anti-anxiety drugs, hypoxia, fever, brain tumors or swelling, immobility, visual impairment, hearing impairment, and dehydration. Early identification and interventions to address these risk factors can significantly reduce the number and duration of episodes of delirium in older patients (Hosker & Bennett, 2016). For example, the patient who normally wears glasses and/or a hearing aid may become confused without these appliances.

The principle of treatment of delirium is to determine and treat the reversible causes of delirium and to mitigate other causes. Determining one cause may be difficult and delay treatment. Delirium may be related to use of medications such as opioids. Changing to a slightly less potent opioid may be effective. Neuroleptic medications (antipsychotics) such as Haloperidol are recommended to reduce agitation in patients with hyperactive delirium; however, they may cause drug-induced Parkinsonism and motor restlessness. Evaluating the clinical need for opiates, anticholinergics, benzodiazepines, and dopaminergics is critical to identify whether any CNS active medications can be discontinued (Hosker & Bennett, 2016).

Fever

Some patients experience a significant fever, which may be evidence of an infection or the body’s response to chemotherapy or radiation therapy. At the end of life, no effort is made to discover the source of the fever, as it will not be treated, and obtaining cultures may be painful for the patient. However, a fever is expected to cause the patient
discomfort. Acetaminophen may be ordered for the patient as an anti-pyretic. If the patient is unable to swallow pills, the acetaminophen may be given via suppository.

Dry Eyes

Patients in a comatose or obtunded state may not fully close their eyes, allowing the uncomfortable possibility of dried corneas. Artificial tears (polyvinyl alcohol 1.4%) may be ordered to be administered every hour around-the-clock to lubricate the eyes, particularly when the eyes are not fully closed.

Nonpharmacologic Pain-Relief Measures

Not all pain relief comes from medications. Other methods, some of them simple, may increase patient comfort and well-being as they augment the effects of drugs. For example, massage or application of heat or cold may help relieve musculoskeletal pain. Repositioning the patient can sometimes relieve pain. Physical therapy may also be beneficial.

Adjuvant therapies for intractable pain include radiation therapy (to shrink tumors or relieve bone pain), radiofrequency ablation for bone pain, surgery to debulk a tumor, nerve blocks, or intrathecal pumps to deliver large doses of opioids without systemic sedative effects.

Complementary therapies such as acupuncture, guided imagery, biofeedback, hypnosis, progressive muscle relaxation (e.g., listening to audiotapes of relaxation techniques), meditation, distraction, and music therapy can also be helpful, not only in relieving pain but also in relieving emotional and psychological distress. Psychotherapy, particularly for patients suffering from depression, can have a positive effect on patients’ perception of pain and response to pain medications. Support groups and pastoral counseling may also be helpful to some patients by reducing psychological distress.

**CASE**

Mr. Willoughby is an 83-year-old hospice patient admitted to the hospital since his family is no longer able to care for him at home. He is unresponsive to all stimuli and unable to swallow. His respirations are 10 to 12 per minute; no other vital signs are being taken. The physician’s orders are as follows:

- DNAR
- Comfort care
- Turn every 2 hours
- Mouth care every 4 hours
- Lip balm every 8 hours
- Family may visit at all hours
Ordered medications include:

- Roxanol (immediate release oral morphine sulfate solution) 20 mg/ml 0.5–1 ml every hour sublingually as needed for signs of pain
- Dulcolax suppository per rectum every day for constipation
- Artificial tears, 1 drop each eye every hour
- Tylenol suppository, 650 mg per rectum every 4 hours PRN for fever or “hot skin”
- Ativan, 1 mg SL every 4 hours PRN agitation

Luanne, his nurse, explains to the family that comfort care status doesn’t mean Mr. Willoughby will not be cared for. She explains that every usual nursing care activity in the hospital, such as collecting vital signs, is considered in terms of the discomfort it may cause the patient and the possible benefits that may be derived. Luanne explains the reasons for each of the physician’s orders and how they help keep the patient comfortable.

Family members express their wish to help and are encouraged to participate in Mr. Willoughby’s care. Luanne demonstrates how to turn the patient and support him with pillows. She tells them that gentle massage to the extremities and frequent application of lip balm to the patient’s mouth will help to keep him comfortable. However, family members are not allowed to administer medications in the hospital, not even over-the-counter remedies.

**PSYCHOSOCIAL SUPPORT ISSUES**

Coming to terms with one’s own mortality is different for each individual and is related to the way he or she handles other life challenges. Compassionate care and support from health professionals and loved ones are essential during this crisis. Adjusting to palliative care involves shifting the patient’s and family’s expectations from curing to healing. Even when cure is no longer possible, healing is.

Lerner (1996) defines healing as “an inner process through which a person becomes whole,” a process of transforming one’s life in a variety of ways in the face of death. This shift in expectations can help maintain hope, seen as crucial in overall adaptation to crisis. For example, the patient who has confidence that pain and suffering can be controlled will have hope for future quality of life. Patients who believe they are loved and cared for will have hope in their relationships.

**Common End-of-Life Emotions**

The person diagnosed with a terminal illness experiences a host of emotions, including those famously described by Dr. Elisabeth Kübler-Ross in her classic 1969 book *On Death and Dying* (Bronstad, 2016). These emotions include the five stages of the grief process: denial, depression,
anger, bargaining, and eventual acceptance. An individual may move back and forth among the stages and may repeat one or more stages.

These and other emotions described below are all normal reactions and deserve equal emphasis with physical care at the end of life. Effective coping with these reactions can improve the quality of life remaining and help the patient resolve important issues with family and friends.

**DENIAL**

According to Dr. Kübler-Ross, denial of a terminal diagnosis occurs when an individual is unable to believe the eventual outcome of death. This may take the form of disbelief in diagnostic test results, questioning whether an error has been made, or maligning the person who has made the diagnosis. Denial usually gives way gradually to an understanding that the diagnosis is, in fact, and accurate one but may evolve to other stages in the grief process before acceptance of the diagnosis occurs, if at all (Bronstad, 2016).

**DEPRESSION**

Health professionals need to distinguish between normal sadness and the level of depression in each patient. Depression is commonly underdiagnosed in the general population; consequently, depression in dying patients may be a preexisting condition. Just as patients require ongoing evaluation for depression and anxiety throughout their course of treatment, so do family caregivers.

The incidence of major depression in patients with advanced cancer and terminal illness ranges between an estimated 6.4% and 17.8%. Less than half of palliative-care patients who have moderate to severe depressive symptoms are on antidepressants (Thomas et al., 2015).

The following factors may suggest the need for early intervention to treat depression as part of end-of-life care:

- History of depression
- Weak support system (few or no family members, few friends, solitary work environment)
- Evidence of persistent irrational beliefs or negative thinking regarding the diagnosis
- Greater dysfunction related to the illness, such as pain, shortness of breath, appetite and sleep dysfunction, and decreased mobility (NCI, 2016b)

The patient who appears depressed should first be assessed for pain. Untreated or undertreated pain can cause depression and other symptoms.
SYMPTOMS OF DEPRESSION

- Feeling sad, anxious, or “empty” most of the day, almost every day
- Decreased interest or pleasure in almost all activities, including sex
- Decreased or increased appetite and/or weight changes
- Disturbed sleep patterns, sleeping more or less than normal
- Fatigue or agitation
- Feelings of worthlessness or excessive guilt
- Inability to concentrate or make decisions
- Recurrent thoughts of death or suicide, or suicide attempts

Depression is treatable both with antidepressant medications and psychotherapy. Depression in dying patients is not markedly different from depression in other medical conditions. However, treatment may need to be modified because of other factors, particularly other medications. Patients with mild depression may be helped by supportive individual or group counseling with a mental health professional. More intense depression will likely require pharmacologic management in addition to counseling. Family and close friends of dying patients may also require counseling and temporary pharmacological management (NCI, 2016b).

Recognizing the symptoms in people with terminal illness and referring them for appropriate treatment can greatly improve their quality of life.

ANGER

Anger is common during terminal illness. Patients may express anger at the illness, the side effects of medications and other treatments (or the failure of same), disruption in life plans, changes in social role and lifestyle, and the prospect of death. Validating that anger is a normal reaction to terminal illness can open a discussion of how to deal with the anger and make the most of the time remaining.

BARGAINING

Bargaining in response to a terminal illness means that an individual promises to change or enact certain behavior for continued life. The bargaining may be proposed with one’s physician, the bearer of bad news, or even God. The idea is that the eventual outcome of death may be changed if the bargain is carried out (Bronstad, 2016). For example, someone with a diagnosis of terminal lung cancer may promise to quit smoking to extend life. Another person may promise to attend church.
ACCEPTANCE

The final stage of Kübler-Ross’s grieving process is acceptance. This may occur when the individual understands that death is imminent and begins to prepare for this outcome. Not all individuals who receive a terminal diagnosis reach this stage (Bronstad, 2016).

FEAR

The most common fears are those of death itself, pain, dying alone, and being a burden. People with strong spiritual beliefs may not fear death but still fear the possibility of pain and suffering at the end of life. Fear can heighten the expectancy of pain and lead to symptoms such as distress, sleep disturbances, anticipatory nausea, and vomiting. Fear can substantially interfere with the quality of life. Health professionals with expertise in palliative care can reassure patients that pain and suffering will be relieved and that patients will not die alone.

Most people also have fears and concerns about loss of dignity and control. Caregivers can provide comfort by allowing the person to express any fears and concerns about dying and by reassuring the person that they will honor advance directives. They include patients in discussions about issues that concern them. They listen to patients reminisce about their lives. They may simply keep the person company; talking, watching movies, reading, or just “being there” also can be comforting (NCI, 2013a).

LOSS, GRIEF, BEREAVEMENT

Life is filled with losses, some minor (lost car keys), some major (job loss), some physical and tangible (losing hair during chemotherapy), others psychological and intangible (losing social contacts). Loss may be sudden and unexpected or anticipated and predicted. The meaning or value of what is lost to the individual determines the feelings that result. Aging and the end of life involve a succession of losses, concluding with the ultimate loss—loss of self. The losses can include:

- Loss of physical strength and abilities
- Loss of mental abilities (confusion/dementia)
- Loss of relationships
- Loss of self-esteem
- Loss of body image
- Loss of independence
- Loss of control over life plans and lifestyle

Experiencing multiple losses often leaves insufficient time to grieve those losses and creates feelings such as hopelessness, withdrawal, isolation, and anger. Physical weakness and/or pain can also diminish the ability to cope with loss.
Grief is a normal human response to loss, and it is universal, individual, and unpredictable. Researchers have described various stages of grief, but people do not always move through such stages sequentially or predictably. Instead, each person progresses at his or her own pace and may recycle through one or more of the stages, which include:

- Shock and numbness
- Yearning and searching
- Disorganization and despair
- Some degree of reorganization

An individual’s experience of grief is determined by his or her values, cultural norms, and circumstances. In uncomplicated grief, an individual is able to move through the stages and emerge from the grieving process. Complicated grief (also called chronic grief or dysfunctional grief) is an exaggeration of the normal process of grieving, often resulting from multiple losses and making it difficult for an individual to reorganize and move on.

The dying patient and the family experience anticipatory grief, a process of working through their intellectual, behavioral, and emotional responses to what the expected death will mean when it happens. During this process, families often try to resolve personal and family issues, offer love and support, involve the dying person in plans for a memorial service, and determine any last wishes not yet spelled out in a legal document.

Bereavement is being deprived of someone through death and the feeling of desolation that follows. For example, a bereaved husband has been deprived of his wife through death. The term can also be applied to families, communities, and even an entire nation. Natural disasters, for instance, cause thousands of deaths and lead to many bereaved family members and loved ones all around the world. The term bereavement does not define all the types of emotions, attitudes, or behaviors that occur in individuals.

(See also “The Family’s Bereavement” later in this course.)

**Religion and Spirituality in End-of-Life Care**

National and international palliative care guidelines acknowledge the importance of religion and/or spirituality in illness, particularly at the end of life, and support care that attends to the spiritual needs of patients (National Consensus Project, 2013). Religious and spiritual beliefs and practices are highly individual, although research shows some racial/ethnic similarities.

Blacks and Hispanics are more likely to consider religion/spirituality more important than whites. Some South Asian faiths believe that prolonging the dying process and interfering with clarity of consciousness ought to be avoided. Muslims believe that death marks the transition from one life to another, and that the treatment of terminal pain is permissible under the distinction of intended actions (Becze, 2013; Samanta, 2013).
Autonomy in end-of-life decisions is an important concept and relates directly to a person’s religious beliefs. The choices stated in living wills and advance directives are as much an expression of a patient’s spiritual authority as they are personal preferences. A faith-based psychological coping framework is as necessary as adherence to a more formal religious doctrine in providing patients and their families with effective coping mechanisms at the end of life. The greater the self-reported religious beliefs, the more optimistic individuals are in their perceptions of outcomes, including greater confidence in treatment efficacy (Churchill, 2015).

Decisions such as whether to withdraw or withhold life-sustaining treatment, to palliate symptoms, or to initiate terminal sedation require consideration of a patient’s religion and beliefs. Perceived or real, inability to perform end-of-life rituals of religious significance can have negative and enduring repercussions that are significant in that spiritual needs may be unrecognized by health professionals.

Research has found that patients may believe their faith helps them cope with impending death and that practices such as prayer, both alone and with others, are meaningful. They may believe that the trajectory of their lives is the plan of a supreme creator but that they should do their best to live right. They may feel that their religion/spirituality transforms how they experience their illness and the end of life, and they often depend on support from their faith community. Understanding these themes and incorporating them into care can improve the quality of life of dying patients and give support to their families (Churchill, 2015).

Family Caregiver Burdens

Family caregivers make up a “shadow workforce” that bears an enormous burden during end-of-life care of a loved one. They play a major role in actual patient care and in decision-making about care provided by others. Informal caregiver networks help ease the multiple burdens placed on primary caregivers. This may include other family members, church groups, neighbors, or volunteer respite workers.

Despite the multitude of available resources, family caregivers of those with chronic disease continually underutilize support services to cope with the demands of caregiving (Eifert et al., 2015). Therefore, healthcare professionals should be aware of some common burdens of family caregiving when communicating and interacting with the family. These are described below.

**TIME AND LOGISTICS**

Caring for a spouse or other family member with serious chronic illness or disability is time-consuming and demanding. Whether caregiving takes a few hours per week or 12 hours a day, the responsibility is continuous. Coordinating medications, treatments, and social services and possibly tending to the needs of other family members can be overwhelming and exhausting, causing caregiver burnout. There are a multitude of support services available to the family caregivers that are underutilized likely because they don’t self-identify as caregivers and do not recognize the need for respite care or other services (Eifert et al., 2015).
PHYSICAL TASKS

The majority of family caregivers are middle-aged or older women who may not have the training or physical stamina necessary to lift, move, or turn terminally ill loved ones. Without professional help, they risk physical injury. Caregivers experience more physical injury than noncaregivers. The most common physical complaints of caregivers are pain, particularly headaches and back pain (APA, 2016). Clinicians need to anticipate this risk and offer assistance with physically strenuous aspects of care.

FINANCIAL COSTS

Even though the Medicare hospice benefit relieves some of the financial burden of serious illness, families can still face severe economic consequences. Many caregivers must give up their paying job and lose wages and benefits or make major life changes. In our society, a large number of caregivers are African Americans and Hispanic Americans who face greater economic hardship from caregiving.

MENTAL AND PHYSICAL HEALTH RISKS

Caregivers experience many emotions, ranging from sadness, resentment, anger, and a sense of inadequacy, to deep gratitude for being able to care for the loved one. Physical exhaustion, economic worries, disrupted routines, and seemingly endless responsibilities can lead to mental health problems such as anxiety and depression. Inadequate or interrupted sleep is also common among caregivers, as is loss of social and leisure time. Lowered immune system and higher blood pressure are also reported issues for overtaxed caregivers (Eifert et al., 2015).

Health problems related to caregiving are most pronounced among women and those with limited education and can include increased risk of cancer as well as increased mortality, particularly among older adults (APA, 2016). Increased stress in caregivers can be overwhelming and could result in elder abuse. Referring the patient for respite care can offer caregivers much needed relief and time to take care of themselves.

SUPPORT AND EDUCATION FOR CAREGIVERS

Various programs and interventions have been developed to assist family caregivers to cope with the demands of caregiving. These support services include assistance with caregiving or related tasks and emotional or educational support that is provided to family caregivers by health professionals and community service providers. Some examples of support services include information and referral, education, support groups, counseling, meal programs, or personal care services such as home health or adult day centers (Eifert et al., 2015).

The negative health effects of caregiving can be at least partially alleviated by thorough assessment of caregiver needs leading to a care plan with support services. Respite care, caregiver support groups, and skills-training interventions can further reduce caregiver burden. Lethin and colleagues (2016) performed an exploratory, cross-sectional study regarding formal...
support for informal caregivers of older dementia patients. Counseling, caregiver support, caregiver education, adult day care, and in-home respite care appeared to have positive results for the caregivers.

END-OF-LIFE CARE FOR SPECIAL POPULATIONS

The Patient Who Has Cancer

There are estimated to be over 14.5 million people currently living with cancer in the United States. Cancer is now the leading cause of death in Americans under age 85. About 1 in 3 women and 1 in 2 men will develop cancer during their lifetime. In 2014, an estimated 15,780 children and adolescents ages 0 to 19 were diagnosed with cancer and 1,960 died of cancer. Although earlier detection and newer therapies have improved five-year survival rates for many types of cancer, 1 in 4 Americans will die of cancer (NCI, 2016c).

- Estimated new cancer diagnoses in 2013: 1,685,210
- Estimated cancer deaths in 2013: 595,690
  (NCI, 2016c)

The most common cancers are breast cancer, lung and bronchus cancer, prostate cancer, colon and rectum cancer, bladder cancer, melanoma of the skin, non-Hodgkin lymphoma, thyroid cancer, kidney and renal pelvis cancer, leukemia, endometrial cancer, and pancreatic cancer.

Aggressive end-of-life care is considered to be chemotherapy within the last two weeks of life, an emergency room visit or hospital or ICU admission within 30 days of death, or admission to hospice within the last three days of life (Wang et al., 2016). Approximately 50% of terminal patients experience some form of aggressive therapy, especially repeated hospital and ED visits. Although hospice use is increasing, many cancer patients are entering hospice care just days before death.

Aggressive end-of-life care may not be in keeping with a patient’s stated preferences. Earlier enactment of palliative care and better communication with patients are considered essential to improving end-of-life care (Wang et al., 2016). Therefore, education for healthcare practitioners about the end-of-life care options for patients and their families is needed so that providers can offer information about possible alternatives to aggressive treatment.

People with terminal cancer have the same physical and emotional needs as any dying person, not the least of which is pain management and its side effects. Not every person with terminal cancer experiences excruciating pain, but it is common. Other physical needs arise as the disease progresses, affecting all major body systems, and should be managed based on the goals of patient comfort and quality of life.

The person with advanced cancer may also be suffering the effects of chemotherapy and radiation therapy. A recent study showed that people with very late chemotherapy use, very short
hospice enrollment, and repeated hospitalization were considered to have poor end-of-life experiences by oncologists. More aggressive treatment occurred less frequently for patients with health maintenance organization (HMO) insurance coverage (Wang et al., 2016). Healthcare professionals need to discuss these issues with the patient and family so they may be better prepared for the time ahead. The person with advanced cancer faces special problems.

**DISRUPTION OF FUNCTION**

As cancer metastasizes to liver, lungs, bone marrow, brain, bowel, and/or adrenal glands, it disrupts the function of those organs. For example:

- Liver metastases can impair digestion and cause nausea and vomiting.
- Cancer that has metastasized to the bowel can interfere with elimination, even to the point of fecal impaction.
- Brain tumors increase intracranial pressure as they grow and can cause changes in mental status, vomiting, headache, dizziness, and seizures.
- Growth of metastatic breast, lung, or prostate cancer may compress the spinal cord and lead to irreversible paraplegia if not treated by radiation to shrink the tumor.

Decisions concerning whether and how to treat these complications should involve the patient and the family as well as clinicians.

**HEMATOLOGIC ISSUES**

Most people with cancer are at least mildly anemic, but chemotherapy and radiation therapy can exacerbate the problem. Erythropoietin (Epogen) has been used to treat the anemia; however in 2010, the Food and Drug Administration (Medline Plus, 2016) issued a safety announcement indicating that the use of Epogen and other erythropoiesis-stimulating agents (ESAs) such as Procrit and Aranesp can increase the risk of tumor growth and shorten survival in patients with cancer. ESAs can also increase the risk of heart attack, heart failure, stroke, or blood clots in patients who use these drugs for other conditions.

A medication guide explaining the risks and benefits of ESAs must be provided to all patients receiving ESAs. Only hospitals and healthcare professionals who have enrolled in and completed a special training program on ESAs are permitted to prescribe and dispense ESAs to patients with cancer.

Cancer that metastasizes to the bone marrow can cause leukopenia (decreased leukocyte count), which increases the risk of infection, and thrombocytopenia (decreased platelet count), which increases the risk of hemorrhage. For example, in liver metastases the tumor may rupture spontaneously and cause hemorrhage.
ANOREXIA-CACHEXIA

Anorexia is loss of appetite, which may be related to both physiological and psychological factors. Cachexia is a malnutrition syndrome that includes anorexia; early satiety (feeling of fullness after only a few mouthfuls of food); weight loss; anemia; weakness; and alterations in taste and in metabolism of proteins, lipids, and carbohydrates. Cachexia results in wasting and emaciation and is one of the leading causes of death in cancer patients.

HYPERCALCEMIA

Hypercalcemia is an elevated level of serum calcium and the most common life-threatening metabolic disorder associated with cancer. Hypercalcemia can occur in nearly 10% to 20% of cancer patients at any stage of the malignancy. Some types of cancerous tumors (particularly lung and breast tumors and multiple myeloma) as well as bone metastases produce a protein that acts as excess amounts of parathyroid hormone. When serum calcium levels exceed the kidneys’ ability to excrete the excess calcium, nausea and vomiting, constipation, muscle weakness, and dysrhythmias result. Diagnosis and timely interventions can be lifesaving in the short term and may improve the patient’s compliance with primary and supportive treatments as well as improve quality of life.

Untreated hypercalcemia leads to loss of consciousness, coma, and death. Depending on the therapeutic goals determined by the patient, the family, and the responsible clinicians, this course of events may represent a preferred timing and/or mode of death when compared with a more prolonged death from advancing metastatic disease. It is important to consider this option long before the onset of hypercalcemia or other metabolic abnormalities that impair cognition so that the patient may be involved in the decision-making (Cancer.net, 2016).

PLEURAL EFFUSION

Pleural effusion is the accumulation of fluid in the pleural space, which can cause pain and difficult breathing. Thoracentesis (needle aspiration) to drain the fluid, which may be a liter or more, relieves the pain and facilitates breathing.

The Patient Who Has Dementia

The widespread misconception that hospice care is only for cancer patients has created a barrier to seeking hospice care for people with other terminal conditions. Among hospice patients, 44.7% have a diagnosis of Alzheimer’s or other dementias, sometimes in addition to other diseases (CDC, 2016b).

Psychiatric management fits well with palliative care. Cross-training mental health with palliative care nurses improves the delivery of care and outcomes for dementia patients. Near the end of life, dementia patients may experience agitation, psychosis, depression, and delirium that may require judicious use of psychopharmacology. Patients often experience pain but may only be able to communicate this through behavioral changes such as uncharacteristic irritability or
withdrawal, increased vital signs, and pained facial expressions. The palliative care approach emphasizes relieving suffering. Applying this philosophy to advanced dementia acknowledges that the patient has a limited life expectancy and is not likely to benefit from an aggressive approach to comorbid conditions (Hawkins, 2016).

Health professionals need to educate families about the benefits of hospice care for their loved one and for themselves. Decisions about end-of-life care for people with Alzheimer’s disease or other dementias should be made as soon as possible after diagnosis while the patient is able to express personal wishes and participate in decisions.

Referral to the local chapter of the Alzheimer’s Association can help families find attorneys who specialize in elder law or estate planning. This referral should not be made abruptly but as a suggestion, emphasizing that every adult, regardless of health status, should make such a plan. This helps ensure that an individual’s wishes are respected in end-of-life care and in the disposition of property after death. Otherwise, families will need to make difficult decisions without knowing the patient’s wishes. Care must be taken to ensure that those involved in elder law and estate planning are well-informed and honest.

PAIN MANAGEMENT

Chronic pain is as prevalent among people with dementia (almost half) as among the elderly in general. Failure to detect pain is especially apparent among those with severe cognitive impairment. Pain in older people is mainly due to degenerative disease of the joints and spine, neuropathic pain, fractures, and cancer.

Patients with dementia may not always be able to verbally communicate their pain. Verbal and visual self-report scales; face pictures; and bedside observation of posture, guarding, facial expressions, and behavior during usual activities may indicate an increase in the pain level. People with dementia are less able to tolerate opioids and other systemic chemical analgesics because of atrophied brain and body size and aging organs that function less efficiently (Flegel, 2013).

NUTRITION AND HYDRATION

In the late stages of dementia, patients may become unable to consume sufficient oral feedings to prevent weight loss. This may be related to poor swallowing, lack of appetite, and a choking cough after eating. Late-stage dementia patients lose significant amounts of body weight. When the patient loses the ability to swallow, he or she is considered terminal. This is a normal occurrence in the final stages of Alzheimer’s disease. Most patients with advanced dementia have a low metabolic rate due to physical inactivity. This can be confirmed by weighing the patient every four weeks. If he or she is maintaining a constant body weight, this rules out starvation and any medical indication for tube feeding (Riachi, 2016).

If the patient’s advance directive indicates that he or she does not want artificial nutrition and hydration (ANH), caregivers and health professionals must respect that decision. However, if the decision was not made earlier, the patient’s surrogate or proxy decision maker, together with the
physician and other members of the healthcare team, must decide together whether to initiate tube feedings. When nurses and other healthcare practitioners are well-informed about ANH issues, they are able to guide family members who have to make decisions for their older relative with dementia.

Families of people with advanced dementia need to understand that their loved ones are unlikely to benefit from tube feeding, either in terms of survival or quality of life. Based on multiple studies in patients with advanced dementia, tube feeding has not been found to improve survival time, reduce mortality risk, or reduce the incidence of pressure ulcers (Dening, 2016).

**The Patient Who Has HIV/AIDS**

According to the CDC, 44,703 persons aged 13 years and older living in the United States have been diagnosed with HIV infection. HIV/AIDS remains an incurable disease, killing approximately 6,721 people in the United States each year (CDC, 2016c).

More effective treatments for HIV/AIDS and for opportunistic infections have made the disease trajectory far less predictable. This has increased the difficulty of making decisions about advance care and end-of-life issues. Although patients with HIV/AIDS agree that advance care planning is important to clarify end-of-life issues, most stated that they have not signed advance directives and that their families are not aware of their wishes.

Older adults with AIDS develop multiple medical conditions. In advanced AIDS, the patient may suffer both the late effects of the disease itself as well as treatment-related toxic effects. The combined effects include fatigue, weakness, memory loss, and continuous diarrhea, which together necessitate around-the-clock care. If family or friends are unavailable to provide care, the services of home health aides are required. These aides need to be informed about whether the patient has a DNAR order in effect and whether the patient wishes to be hospitalized (Slomka et al., 2016).

The person living with advanced AIDS has some of the same psychosocial concerns as patients with any terminal illness, including financial issues, bereavement issues, and fear of death. In addition, the individual may have unique issues related to HIV/AIDS, which can include:

- Stigmatization related to HIV/AIDS
- Fear of contagion and disfigurement
- Fear of social isolation and abandonment
- Lack of motivation to take precautionary measures
- Denial of gainful employment
- Poor quality of treatment
- Lack of traditional support systems

(Dahlui et al., 2015)
Many lack the traditional support systems of friends and families. Friends may be HIV-infected themselves. Others may be afraid of contagion, based on ignorance about HIV transmission or unresolved homophobia. Families may live far away, since many people with AIDS have migrated to large urban areas that are more tolerant of nontraditional lifestyles, perhaps leaving them without a support system or socially isolated when their disease progresses. Persons may lose their jobs or not be able to obtain other work.

One-on-one counseling or a grief support group can help the bereaved patient and afford an opportunity to discuss his or her own concerns and fears about the death of a friend or loved one.

Dying Children and Their Families

Learning that their child has a life-threatening illness and preparing a child for death is one of the most unnatural and difficult events in any parent’s life. Yet each year parents across the United States confront this tragedy as 50,000 children die from life-threatening conditions: extreme prematurity, severe birth defects and congenital anomalies, cancer, HIV/AIDS, progressive metabolic disorders, and other diseases and disorders. The current infant mortality rate (meaning death occurring before the first birthday, generally from conditions existing at birth) is 5.8 per 1,000 (CIA, 2016).

The remarkable resilience of children can make it difficult to predict whether treatment of life-threatening conditions will end in cure or death. More than half a million children in the United States are coping with complex chronic and life-threatening conditions. These children and their families need and deserve palliative care beginning at the time of diagnosis so that treatment is not limited to the disease process itself. This gives families more time to cope with the possibility that their child will die even as they hope for cure.

If it becomes clear that cure is no longer possible, the child may be able to receive hospice care at home rather than in the hospital. Conveying to the child that he or she will not be alone as they near the end and that parental support and love will continue even afterward can be most helpful to a dying child (LLS, 2016).

For example, Massachusetts has a Pediatric Palliative Care Network of hospices that provide free palliative care to children (under 18 years old) with potentially life-limiting illnesses and their families, not just those who have a 6-month prognosis. It offers a total approach to care—physical, psychological, social, and spiritual. Services include pain and symptom management for the ill child, counseling and spiritual care for parents and siblings, and volunteer assistance with errands (PPCN, 2014).

PAIN MANAGEMENT

Physical care of the dying child is focused on comfort, using the least invasive procedures while protecting privacy and dignity. A child with terminal illness has the same physical needs as any seriously ill child, including pain management, regular sleep and rest, nutrition, maintenance of bowel and bladder function as well as respiratory function, and skin care. Additionally, several
studies have shown a high degree of symptom burden in children with terminal illness in the last few weeks of life. These symptoms include pain, dyspnea, fatigue, lack of appetite, nausea and vomiting, constipation, and changes in sleep patterns (Vitas Healthcare, 2016).

Children who are dying share the same fear of pain as adults with terminal illness. Infants are believed to be even more sensitive to pain due to underdeveloped inhibitory pain tracts (Vitas Healthcare, 2016). Care providers need to talk with the family about pain management before the need becomes severe. Parents are greatly concerned that their child not suffer at the end of life. In a study at Boston Children’s Hospital/Dana Farber Cancer Institute, 89% of parents stated that their children “suffered a lot” in their last month of life as a result of receiving aggressive treatments.

When pain or other symptoms are not treated or are treated unsuccessfully in their dying child, parents are likely to experience long-term distress. For most children pain control can be achieved using standard dosing with medications such as opioids and benzodiazepines (Vitas Healthcare, 2016). Families who express concerns about addiction from narcotic pain medication need to be reassured that there is no evidence to support the idea. Like adults, children may develop a tolerance to sedatives and opioid medications, so that the dosage or the choice of drugs may need to be changed.

COMMUNICATION WITH PARENTS

Parents of children who have life-threatening conditions want to be kept informed about their child’s condition and what to expect throughout the course of the illness. They may also want information about caring for their child at home and about how to support siblings of the ill child.

Effective, skilled, and sensitive communication is essential in all aspects of children’s palliative care. Linguistic, religious, and cultural differences may prove especially challenging in pediatric palliative care. These issues can interfere with parents’ ability to participate fully in their child’s care and “contribute to frustration, anger, and sadness for parents long after their child’s death” (TSL, 2014). Therefore, healthcare practitioners need to ensure that all parents receive clear, factual information and that the family can understand and respond to questions and emotional concerns. This fosters trust in the relationship and reduces distress and anxiety in the parents and family.

6-STEP PROTOCOL FOR SHARING SIGNIFICANT/BAD NEWS

1. Getting started
   • Plan what to say
   • Create a conducive environment
   • Allot adequate time
   • Determine who else needs to be part of the conversation
2. Determining what the patient knows
   - Establish what the patient knows
   - Establish what the child’s parents know
   - Assess ability to comprehend new bad news
   - Reschedule if unprepared (discuss)

3. Determining how much the patient wants to know
   - Recognize and support patient preferences
   - Advance preparation
   - Handling difficult cases

4. Sharing the news (“WPC” chunk method)
   - W Warn
   - P Pause
   - C Check back

5. Responding to emotions
   - Prepare for strong emotions
   - Listen
   - Validate the response
   - Take time
   - Encourage descriptions of the feelings
   - Use appropriate nonverbal communication

6. Planning follow-up
   - Identify options
   - Suggest sources of support
   - Start a plan
   - Schedule follow up appointment/conversation
   - Ensure family has a contact name and number
   - Before they leave, assess support at home and safety of the patient and family


END-OF-LIFE ISSUES FOR INFANTS

Advances in medicine, surgery, technology, and skilled nursing care have vastly improved the survival of premature and other high-risk infants. However, sometimes the very best care and the strongest hopes and prayers are not enough to save these fragile lives.
The child who dies before age 1 year will likely have been hospitalized for much of his or her life. The challenge for health professionals is to make that time as comfortable and meaningful as possible for the infant and the family, supporting their need to be together, to touch each other, to create shared memories, and to prepare for the loss ahead.

Parents need a nurse or physician who can provide an overview on the infant’s condition every day. This helps avoid misunderstandings from fragmentary information. Parents need to know that it is okay to ask questions and expect honest, understandable answers about what is going on. Other children in the family as well as the grandparents also need to be involved. Taking photographs of the infant with family members is important, particularly for those parents whose infant will never get to go home with them.

**COMMUNICATING WITH CHILDREN**

Children with a terminal illness still enjoy age-appropriate play activities—games, drawing, coloring, seeing friends. School-age children who are able to attend classes should be encouraged to do so to maintain a sense of normalcy and stay connected with their peer group. Frequent absences are common, but some children want to continue their studies at home as long as possible.

The dying child and the family need to try to talk about death with each other, although it can be difficult and painful. It is essential to be honest when discussing end-of-life issues with a child, but to also refrain from scaring them (LLS, 2016). Parents worry that talking about death will cause the child to lose hope and thus the will to live. But keeping the diagnosis secret denies the child’s right to express feelings, fears, and questions. Children pick up cues from parental and/or sibling behavior that something bad is going to happen, and they need to express their feelings.

There is documented evidence that all patients, even very young children, know they are dying and that they are able to recognize the exceptional distress among family and caregivers around them when death becomes close. By age 6, children begin to recognize the fact of death and what it means. By age 10, children know that death is final. References to its imminence can be quite direct and explicit, however most pediatric patients can tell when adults’ are having difficulty talking to them about end-of-life issues, death, and dying, and they begin to feel isolated and alienated. If an open and honest dialogue has been established from the beginning, it will be reflected in the willingness of the child or adolescent to talk about fears regarding death (LLS, 2016).

Keeping the diagnosis secret also risks having someone else reveal the information, eroding the child’s trust in the parents. Health professionals can offer support and guidance to the parents by asking, “How will you tell your child the diagnosis?” and then suggesting how and what to tell the parents based on the child’s age. Naming the illness helps explain what to expect in terms of procedures and possible outcomes. Once the child learns the diagnosis, he or she may choose not to talk about death. Parents and health professionals need to respect that wish.

Communicating with children about death involves more than just words. It is important to ask the child questions about what they understand and what they’re feeling. Reassurances are given
that all of those feelings are acceptable, even sadness, anger, and tears (LLS, 2016). Health professionals need to assess the child’s body language and encourage expressive outlets for feelings, such as drawing; play with dolls, puppets, or stuffed animals; writing stories; or working with modeling clay.

Both the child and the family generally fear what the actual death will be like, particularly whether it will be painful. The child fears dying alone; the family fears not being with the child when death occurs. Having family members nearby enhances the child’s feelings of security and safety. Physical contact—touching, hugging, holding hands—is comforting and helps the child feel more secure. When parents or siblings need to leave, it helps to tell the child when they will be back.

| AGE-RELATED CONCEPTS OF DEATH IN CHILDREN |
|-------------------------------|-----------------------------------------------|
| **Age**                      | **Concepts**                                  |
| Up to 6 months               | • Loss brings no response due to undeveloped memory capacity for specific personal relationships  |
|                              | • No ability to conceptualize death            |
| 6 months to 1 year           | • Loss, like separation, may be felt, if at all, as a vague absence or experiential sense of “something different” |
| 1 to 2 years                 | • Death of primary caregiver will usually result in displeasure and depression |
|                              | • No ability to understand or attribute meaning to a loss |
|                              | • Can be influenced by a parent’s tense and emotional grief reactions to death |
| 2 to 6 years                 | • Death understood as temporary and reversible |
|                              | • No concept of a personal death; death only happens to others |
|                              | • Belief that dead persons or animals are broken and can be fixed, asleep and can be awakened, gone and will be back |
|                              | • Often think about and are quite interested in death (well-developed, intelligent, curious 4- to 6-year-olds) |
|                              | • Often want to see and touch dead things (well-developed, intelligent, curious 4- to 6-year-olds) |
| 6 to 9 years                 | • Developing a clearer understanding of death from 6 to 8 years |
|                              | • Increased interest in the physical and biological aspects of death |
|                              | • “Magical thinking” predominates, with the belief that thoughts can make things happen, even accidents and death |
| By 9 years                   | • Concept of death is very similar to an adult’s |
|                              | • Death is not reversible or temporary but only happens to other people |
|                              | • Death often thought of as a person or a “ghost” figure |
### End-of-Life Care

9 to 12 years
- Concept of death expands to that held in adult life
- Fully developed awareness of the possibility of personal death
- Objective curiosity develops: “What does the body look like?”, “Is the blood blue, the body stiff, cold, etc.?”
- Strong tendency toward denial even though there is a cognitive awareness of death and its universality and finality
- Increased interest in what happens after death

12 years through adolescence
- Death now viewed abstractly and subjectively
- Strong egocentrism and a tendency to think of oneself as immortal
- Subjective curiosity develops: “What is the meaning of life?”, “What is my special mission?”, “Why doesn’t anyone besides me understand the implications of life and death?”
- Death often romanticized as beautiful and tragic; paradoxically, a gesture or statement that will somehow endure
- Due to television and movies, see loss experienced through death as easy to deal with


### CASE

Ryan is a 6-year-old boy with terminal cancer who has been undergoing chemotherapy off and on for the past three years. He is now considered end-stage and is being discharged from the Children’s Hospital pediatric hematology/oncology (Hem/Onc) unit to go home for hospice care. His oncologist, Hem/Onc nurse, and parents have explained the situation honestly and at a level he can understand, creating an open climate where he feels able to ask any questions or express any concerns.

Ryan is happy to be going home and in knowing that he will not have to come back to the hospital or undergo chemotherapy again. He understands that he will soon die and believes he will go to heaven and be able to “look down” on his family and friends. He tells his primary nurse good-bye and thanks her. He has told his parents he is afraid of being alone when “dead comes,” and they have reassured him that someone from his family will be with him at all times. An organization called the Carousel Fund in his hometown provides funds to families with catastrophic illnesses so at least one parent can be with the child.

### LEGAL ISSUES

The legal responsibility for decisions about a child’s treatment rests with parents. However, clinicians should encourage parents to involve the child in decisions about continuing treatment aimed either at cure or at moving to palliative care. Adolescents may have very definite ideas about the course their treatment should take.
Both the child and the family need to understand what palliative care means. For example, they need to know the risks as well as the potential benefit of CPR. Clinicians should explain that “no code” does not mean “no care” but just a different kind of care aimed at comfort and maximum enjoyment of the time they have left with their child.

**FINANCIAL ISSUES**

Children are not covered by the Medicare hospice benefit. Consequently, hospice care for children can impose a tremendous financial burden on families, which is one reason why so few children under age 17 are in hospice care.

Medicaid, a jointly funded federal-state health insurance program for people who need financial assistance for medical expenses, must provide home care services to people who receive federal income assistance such as Temporary Assistance to Needy Families (TANF, 2015). Medicaid coverage includes part-time nursing, home care aide services, and medical supplies and equipment. Information about coverage is available from local or state welfare offices, state health departments, state social services agencies, or the state Medicaid office.

**BEREAVEMENT**

Bereavement begins in the period before the child dies in the form of anticipatory grief and extends well beyond the time of death. Care of the family should extend into the bereavement period. If the child is enrolled in hospice care, bereavement support for the family is part of the services provided. However, if the child dies in the hospital, there may not be a formal bereavement care program available.

One study on the effect of caregiving on bereavement—which measured caregiving experiences (strain, distress, positive appraisals, and family well-being); caregiver prolonged grief responses (despair, panic behavior, blame and anger, detachment, disorganization, and personal growth); prolonged grief; quality of life; general health (psychological and physical); and demographics—determined a need for more sustained pre- and post-bereavement care (Breen et al., 2015).

**Veterans**

Veterans account for 25% of all deaths in the United States (We Honor Veterans, 2016). Most veterans die either at home, in a nursing home or assisted-living facility, or in a residential hospice. Veterans may receive hospice care through the Veterans Administration (VA). The VA may purchase hospice services from community providers to give service in home, hospital, or long-term care facility.

Veterans’ benefits include palliative care and hospice care, but some veterans may not know about or understand these benefits. All VA facilities have a Palliative Care Consult Team (PCCT) as a resource for hospice and palliative care provided in the VA facility and coordinated in the community. Although local VA medical centers have the flexibility to address end-of-life
care according to veterans’ needs, national policy and standards stipulates that each VA facility have the following resources and services:

- A designated hospice contact person who is part of an integrated network for local and national communications and information dissemination
- Provision of needed hospice services in all settings
- Inpatient hospice beds or access to them in the community
- An interdisciplinary palliative care consultation team
- Assistance with referrals to community hospices in its service area
- Tracking of hospice and palliative care services provided to veterans in all settings (NHPCO, 2016b)

Health professionals need to be aware that veterans dying in the VA system may have a higher degree of social isolation, lack of family support, or lower income than those outside the system. In addition, military training may have created in them an attitude of stoicism and a barrier to admitting pain or requesting pain medication. On the other hand, being in a hospice with other veterans offers a camaraderie that can be comforting.

Showing respect for a veteran and acknowledging service to the country is a first step in establishing a relationship. Simply asking, “What branch of the service were you in?” can be a key assessment question. Other factors that influence experiences at the end of a veteran’s life include age, whether enlisted or drafted, rank, and combat or POW experience. More than 1,600 hospices across the country participate in the We Honor Veterans campaign every year (We Honor Veterans, 2016).

**DEATH OF THE PATIENT**

**The Final Hours**

Care during the last hours of life, called active dying, can have profound effects on the patient, the family, and healthcare practitioners who attend the dying. In acute care, multidisciplinary healthcare workers must transition from curative to comfort care. The family needs proximity, privacy, and support as they transition from grief to bereavement. Follow-up bereavement services for the family are greatly appreciated (Fridh, 2014).

Comfort care provides immediate relief of symptoms for a patient who is actively dying. Many distressing symptoms that the dying patient has been facing—such as pain, irritability, failing senses, and signs of dehydration—may exacerbate as death becomes imminent. A plan of care is usually established by the patient or family and healthcare personnel to determine withdrawing or prevention of life-sustaining measures, cessation of diagnostic tests, consideration of nutrition and hydration, and selection of comfort measures. Some ethical challenges at this time may be
related to changed sedation practices, organ donation, and cultural sensitivity (Blinderman & Billings, 2015).

**SIGNS OF IMMINENT DEATH**

Certain signs and symptoms indicate when death is near (see table below). Not every patient experiences each of these signs and symptoms, and the presence of one or more of these symptoms does not necessarily indicate that the patient is close to death. The final stage of dying may take from 24 hours to as long as 10 to 14 days.

When it is apparent that death is imminent, health professionals need to alert the family and confirm the goals of care. This discussion should be documented in the patient’s chart, including the observation that the patient is dying.

### SIGNS AND SYMPTOMS OF IMMINENT DEATH

<table>
<thead>
<tr>
<th>Signs and Symptoms</th>
<th>Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drowsiness, increased sleep, or unresponsiveness</td>
<td>When speaking, remember that the patient may be able to hear even if there is no response. Advise family members to address the patient as though he or she can hear. Do not shake the patient if he or she does not respond.</td>
</tr>
<tr>
<td>Confusion about time, place, and/or identity of loved ones; hallucinations about people and places not present</td>
<td>Gently remind the patient of the time, date, and people who are present. Be calm and reassuring.</td>
</tr>
<tr>
<td>Decreased socialization and withdrawal</td>
<td>Speak to the patient directly and offer reassurance that he or she is not alone. The patient may need permission from the family to “let go.”</td>
</tr>
<tr>
<td>Decreased need for food and fluids; loss of appetite</td>
<td>If the patient can swallow, offer ice chips, water, or juice. Keep the patient’s mouth and lips moist with glycerin swabs and lip balm.</td>
</tr>
<tr>
<td>Loss of bladder or bowel control</td>
<td>Keep the patient as clean, dry, and comfortable as possible. Use disposable pads on the patient’s bed and remove them when soiled. If urine output is excessive, a catheter may be used. In the case of continuing diarrhea, a rectal tube may be used.</td>
</tr>
<tr>
<td>Darkened urine or decreased amount of urine</td>
<td>A catheter may be necessary to avoid blockage.</td>
</tr>
<tr>
<td>Body temperature lowers; skin cool to the touch, particularly extremities; skin color darkens to a grayish hue; fingernail beds appear cyanotic</td>
<td>Use blankets to warm the patient, who may not be aware of feeling cold. (Do not use electric blankets or heating pads, which can cause burns.)</td>
</tr>
</tbody>
</table>
Rattling or gurgling breath sounds; irregular or shallow breathing; fewer breaths per minute; breathing that alternates between rapid and slow (called Cheyne-Stokes respiration) | Turning the patient’s body to the side and placing pillows beneath the head and behind the back may ease breathing. Supplementary oxygen may benefit some patients. If the patient can swallow, offer ice chips. A cool mist humidifier may make breathing more comfortable.

| Turning the head toward a light source | Leave soft, indirect lights on in the room.

| Increased difficulty controlling pain | Provide pain medications as prescribed. Advise the primary care provider if dose seems inadequate. Gentle massage and relaxation techniques may help with pain.

| Myoclonus (involuntary movements), changes in heart rate, loss of reflexes in arms and legs | When myoclonic jerking is severe, drugs may be used to calm the patient down, relieve anxiety, and help the patient sleep.

Source: NCI, 2013b.

**SIGNS OF DEATH**

Signs that death has occurred include:

- Lack of respiration or pulse
- Eyes open but do not move or blink; pupils dilated
- Jaw relaxed; mouth slightly open
- Bowel and bladder contents expelled
- Patient does not respond to touch or speech
- Skin color becomes pale and waxy in appearance
- Body temperature drops
- Sound of internal fluids trickling or gurgling

When death has occurred, nurses or other clinicians need to express their sympathy to the family. It is enough to say, “I am sorry for your loss.”

**CASE**

Agnes, an elderly woman, had been discharged from the hospital to her home to spend her last days in comfortable, familiar surroundings, per her written wishes. Her grandson asked the hospice nurse, “How can we be sure that my grandmother has passed?” The nurse explained that the breathing may become slower, shallow, and loud, even sound like gasping when death is imminent. She showed the grandson where to feel for radial pulse in the wrist and explained that he would be unable to feel it when the heart stopped beating. The nurse told him that all of
the muscles would relax and that this might appear as open eyes, a slack jaw, and incontinence of the bowel and bladder. The skin would become cool, pale, and waxy. When that happened, the grandson was instructed to call the hospice nurse.

Postmortem Care

Death must be certified by a physician in a formal process called pronouncement and the findings related to cause of death documented in the patient’s medical record. Pronouncement may be done by a physician, nurse practitioner, nursing supervisor, or hospice nurse, depending on the state regulations and the policies of the agency involved. Unless the death occurred under unusual circumstances, an autopsy (postmortem surgical examination) is not usually required.

CARE OF THE BODY

Care of the body after death is often the responsibility of nurses and nurse assistants. How the body is cared for after death is often influenced by religion and/or culture, so health professionals should be aware of any preferences or limitations and comply with them. For example, a Muslim may wish to face Mecca to pray when death is imminent. The body will be washed by family or friends to prepare it for the funeral. The eyes will be closed, the arms will be positioned across the chest, and the body will face Mecca (Memory Tree, 2016).

If the family was not present at the time of death, the nurse or other responsible practitioner may make the body and the environment appear as normal as possible for the family to visit. If the patient or family has chosen cremation, or if there is no open-casket service planned, this will be the final opportunity for them to see their loved one.

All equipment and supplies are removed from the bedside and any soiled linens removed from the room. Local regulations may differ on how to deal with tubes that were in place at the time of death. Generally, the coroner must be notified, and no internal tubes can be removed until the patient is cleared by the coroner’s office.

Placing the body in a supine position with a pillow under the head and shoulders avoids discoloration of the face. Eyelids are closed (holding them closed for a few seconds helps them to remain closed). If the person wore dentures, those are inserted to give the face a more natural appearance. Placing a rolled towel under the chin will hold the mouth closed. The arms are positioned either at the sides of the body or across the abdomen. The identifying wristband is left on unless it has become too tight due to fluid retention, in which case it is replaced with a looser one.

Any soiled areas of the body are washed and absorbent pads are placed under the buttocks. A clean gown is placed on the body and the hair is brushed or combed. Any jewelry is removed, except for a wedding band, which is taped to the finger. The body is carefully covered up to the shoulders with clean bed linens. All belongings of the deceased are listed and placed in a safe storage area for the family.
Soft lighting is generally preferred, and chairs may be made available for family members. Clinicians need to reassure family members that they should take as much time as they need to say their last good-byes. Only when the family leaves the room should final preparations for removal of the body be initiated.

**REMOVING THE BODY**

After the family has viewed the body, the care provider attaches additional identification tags, one to the left great toe, another to the wrist (if the deceased person’s wristband has been removed), and one on the patient’s belongings. The entire body is then placed in a white, plastic body bag, and another identification tag affixed to the outside zipper. Then the body is either picked up by the responsible mortician (undertaker) or sent to the morgue until arrangements are made with a mortician.

Some hospitals or other agencies close the doors to all other patient rooms before transporting a body through the corridors and require the use of service elevators rather than public elevators during this transfer.

**Autopsy**

Autopsy is no longer a routine procedure in most hospitals. In 1971 the Joint Commission ceased requiring a minimum number be performed for a hospital to receive accreditation, and in 1995 the National Center for Health Statistics ceased collection of autopsy statistics. Academic hospitals perform autopsies on approximately 10% of all institution deaths, while nonteaching hospitals may not perform any. The national average is currently about 8% (Baumgartner & Anthony, 2016). The procedure contributes to medical education, aids in the characterization of newly emerging diseases, and advances the understanding of disease-related changes. In addition, autopsy can reveal errors in clinical diagnosis.

In the event that autopsy is required, health professionals need to determine whether the family has any religious or cultural concerns about this procedure. Families also need to know that autopsy does not disfigure the body and would not interfere with having an open-casket service.

**Organ Donation**

The growing disparity between organ availability for transplantation and the number of patients in need has challenged the donation and transplantation community. The number of organs available for transplantation has been a relatively fixed national resource over the last decade. By contrast, the national waiting list rises by thousands each year, with only a fraction of those waiting receiving lifesaving transplants.

Organ procurement organizations (OPO) throughout the country facilitate the donor organ recovery, which increases efficiency and organ yield, reduces costs, and minimizes organ acquisition charges. OPOs have taken on the responsibility of harvesting donor organs and matching them with potential recipients (Doyle et al., 2016).
One organ donor may save up to eight lives (Live on NY, 2016). The public has a generally favorable attitude about organ donation for transplants; however, not every clinician broaches the subject with patients since they may be perceived as being more an advocate for the organ recipient than of their patient.

Ideally, questions about organ donation are discussed with the patient in the context of advance directives. This relieves the family of making the decision during the stressful time immediately after death. Unless the patient has documented the wish to become an organ donor, the family must decide.

The 2006 Anatomical Gift Act compels hospitals and OPOs to pursue donation in cases of brain death in designated donors (Stahler et al., 2014). Federal law requires that only a designated representative of an OPO or a “designated requestor” may approach the family about organ donation. A designated requestor may be a physician or other health professional who has completed a course approved by an OPO on how to approach potential donor families to request organ or tissue donation. Who this person is varies according to the facility.

THE FAMILY’S BEREAVEMENT

A family’s bereavement begins when their loved one is diagnosed with terminal illness, initiating a period of anticipatory grieving for both patient and family. After the patient dies, family members continue to grieve until they become reconciled to life without the deceased. For some, the process may take weeks or months; for others, grieving may take a year or longer. The Medicare hospice benefit includes bereavement care for the family for one year after the patient’s death (NHPCO, 2015).

All healthcare practitioners may encounter bereaved persons, and they need to recognize the signs of grieving and bereavement and offer appropriate support as part of care.

Characteristics of Grief

How a person grieves depends on his or her personality, relationship with and attachment to the person who died, and the situation surrounding the loss. Grief reactions can be psychological, emotional, physical, or social. Psychological and emotional reactions can include anger, guilt, anxiety, sadness, and despair. Physical reactions can include difficulty sleeping, appetite changes, somatic complaints, or illness. Social reactions can include feelings about taking care of others in the family, the desire to see or not see family or friends, or the desire to return to work (Holland et al., 2015). If the deceased was the primary earner, the family may suffer stress from significant financial loss.

DeSpelder and Strickland (1987) identified five characteristics of grief:

- Somatic distress
- Preoccupation with the image of the deceased
• Guilt
• Hostile reactions
• Loss of the usual patterns of conduct

Lindemann (1994) described three tasks of what he called “grief work.” These include:

• Freedom from ties to the deceased
• Readjustment to the environment from which the deceased is missing
• Formation of new relationships

To free oneself from the deceased, a person must change the emotional energy invested in the lost person. This does not mean the deceased was not loved or is forgotten but that the grieving person is able to turn to others for emotional satisfaction. To readjust, the grieving person may need to modify his or her roles, identity, and skills to live in the world without the deceased. To form new relationships, the person redirects the emotional energy once invested in the deceased to other people and activities.

Grief work requires significant effort, so it is not uncommon for those who grieve to experience overwhelming fatigue. The grief experienced is not only for the loss of the person who died but also for the loss of wishes, plans, and fantasies that were held for the person and/or the relationship. Death often awakens emotions of past losses or separations. Bowlby (1961) described three phases of mourning: 1) the urge to recover the lost person, 2) disorganization and despair, and 3) reorganization. These phases originated from the attachment theory of human behavior, which postulates people’s need to attach to others in order to improve survival and reduce risk of harm.

Caregiver Grief

When a loved one has experienced a prolonged dying process, some family members not only grieve the loss of that person but also suffer the loss of their role as caregivers. They may experience a sense of relief that the burden of caregiving has lifted as well as guilt for feeling relief. These are natural reactions, and health professionals should encourage their expression.

Health professionals who work with dying patients and their families may also grieve when a patient dies even though the death was expected. In the aftermath of the death of a patient, grief counseling in the form of a debriefing may be offered to the involved staff. Attending the funeral or memorial service may allow expression of the grief as well as show respect for the family and their loss.

Bereavement Resources

Bereavement options for families include grief support groups (either self-help or facilitated by professionals) and one-on-one counseling by a psychologist, psychiatrist, clinical social worker,
or clergyperson. Many online support groups are also available but should be used as an adjunct to in-person therapy rather than as a substitute. If depression occurs in the context of bereavement, medication may be appropriate. No consensus exists among professionals as to the most effective intervention. There are many books and videos available, most of them specifically focused on a particular family role (parents, children, siblings, or spouse).

Hospice professionals who work with the bereaved maintain contact with the family, make home visits, and encourage family members to talk about their feelings, emphasizing that grieving is a painful process that may take years to resolve. It is important to refer to the deceased person by name and to discuss shared memories with the family. Continuing contact with the family offers them an anchor during a difficult time. A good condolence letter offers a tribute to the deceased and comfort to the survivors.

CONCLUSION

Americans are beginning to admit that death is inevitable and that planning for end-of-life care is essential to ensuring that our preferences are respected when we can no longer care for ourselves. More people are drawing up advance directives, appointing a healthcare proxy/agent, choosing hospice and palliative care over aggressive treatments, or considering “assisted death.” This growing awareness around end-of-life issues would not have come about without the educational and outreach efforts of nurses, other health professionals, public health agencies, and private foundations.

The ranks of people over 65 continue to swell as the first Baby Boomers turned 65 in 2011. Many of them have one or more chronic diseases. Thus, the need for high-quality end-of-life care will only increase. The ranks of children needing end-of-life care have also swollen, causing overtaxed parent-caregivers to seek support in the form of bereavement care, respite care, and spiritual guidance.

All healthcare professionals have a role in helping their patients and families understand the range of options available and the benefits of planning for end-of-life care before it is needed.

RESOURCES

American Academy of Hospice and Palliative Medicine
http://aahpm.org/

Caregiver Action Network
http://caregiveraction.org

Center to Advance Palliative Care
Hospice Net
http://www.hospicenet.org

Hospice & Palliative Nurses Association
http://hpna.org

Hospice Foundation of America
http://hospicefoundation.org

National Association for Home Care and Hospice
http://www.nahc.org

National Hospice and Palliative Care Organization
http://www.nhpco.org

National POLST Paradigm: Programs in Your State
http://polst.org/programs-in-your-state/

REFERENCES


Center to Advance Palliative Care (CAPC) and National Palliative Care Research Center (NPCRC). (2016). America’s care of serious illness: 2015 state-by-state report card on access to palliative care in our nation’s hospitals. Retrieved from https://reportcard.capc.org/


© 2017 WILD IRIS MEDICAL EDUCATION, INC.


Dening KH. (2016). Palliative and end-of-life care for people with dementia. Nursing Standard, 30(23), 42. doi:http://dx.doi.org/10.7748/ns.30.23.42.s46


Mankes RF & Silver CD. (2013). Quantitative study of controlled substance bedside wasting, disposal and evaluation of potential ecologic effects. Science of the Total Environment, 444(1), 298ERLI.


DISCLOSURE

Wild Iris Medical Education, Inc., provides educational activities that are free from bias. The information provided in this course is to be used for educational purposes only. It is not intended as a substitute for professional healthcare. Neither the planners of this course nor the author have conflicts of interest to disclose. (A conflict of interest exists when the planners and/or authors have financial relationship with providers of goods or services which could influence their objectivity in presenting educational content.) This course is not co-provided. Wild Iris Medical Education, Inc., has not received commercial support for this course. There is no “off-label” use of medications in this course. All doses and dose ranges are for adults, unless otherwise indicated. Trade names, when used, are intended as an example of a class of medication, not an endorsement of a specific medication or manufacturer by Wild Iris Medical Education, Inc., or ANCC. Product trade names or images, when used, are intended as an example of a class of product, not an endorsement of a specific product or manufacturer by Wild Iris Medical Education, Inc., or ANCC. Accreditation does not imply endorsement by Wild Iris Medical Education, Inc., or ANCC of any commercial products or services mentioned in conjunction with this activity.

ABOUT THIS COURSE

You must score 70% or better on the test and complete the course evaluation to earn a certificate of completion for this CE activity.

ABOUT WILD IRIS MEDICAL EDUCATION

Wild Iris Medical Education offers a simple CE process, relevant, evidence-based information, superior customer service, personal accounts, and group account services. We’ve been providing online accredited continuing education since 1998.

ACCREDITATION INFORMATION FOR WILD IRIS MEDICAL EDUCATION
TEST

[ Take the test online at wildirismedicaleducation.com ]

1. According to a study cited in this course, most Americans would prefer to die in:
   a. The hospital.
   b. A long-term care facility.
   c. Their own home.
   d. A hospice.

2. Hospice care is now available more than ever, but:
   a. Fewer people are eligible for hospice care.
   b. Medicare no longer covers hospice care.
   c. The median length of stay in hospice is far less than optimal.
   d. Hospice benefits are not provided to veterans.

3. Which is a correct statement about the preferences for end-of-life care found among patients of different racial or ethnic backgrounds?
   a. White patients are more likely to prefer spending their last days in the hospital compared to other racial groups.
   b. Hispanic patients mostly prefer life-prolonging drugs and mechanical ventilation.
   c. White patients are far more likely than minority patients to receive hospice care.
   d. Chinese patients prefer more proactive treatment options than patients of other ethnicities.

4. A core belief of palliative care programs is:
   a. Providing services preferably in a hospital-based setting.
   b. Avoiding therapies that prolong a patient’s life.
   c. Controlling only the symptoms of advanced cancer.
   d. Providing care to relieve a patient’s pain and suffering.

5. Which term is often used as an alternate to the term palliative care?
   a. Supportive care
   b. Discomfort care
   c. Pain relief care
   d. Emotional care
6. Hospice services have the primary aim of:
   a. Bringing palliative care to adult patients with advanced cancer.
   b. Providing interdisciplinary care to patients with terminal illness.
   c. Supporting patients to receive end-of-life care at in-patient facilities.
   d. Alleviating suffering by shortening a terminal patient’s survival.

7. To access the Medicare hospice benefit, a patient must agree to forgo treatments such as chemotherapy and radiation, and his or her physician must certify that the patient:
   a. Is diagnosed with advanced cancer.
   b. Is without a living will.
   c. Likely has six months or less to live.
   d. Will not require further hospital care.

8. Physician aid in dying (PAD) is legal:
   a. In all 50 states and the District of Columbia.
   b. In Canada, but not in the United States.
   c. Only in a few states.
   d. Only with the permission of the dying patient’s family.

9. The goal of proportionate palliative sedation (PPS) is:
   a. Unconsciousness.
   b. Relief of nausea and vomiting.
   c. Seizure control.
   d. Relief of intractable pain and suffering.

10. According to the Heart Rhythm Society, removing or deactivating cardiovascular implants near the end of life:
    a. Is synonymous with euthanasia.
    b. Is something that all patients have the right to decide.
    c. Must be decided by the patient’s cardiologist.
    d. Conflicts with all codes of medical ethics.
11. Although advance directives are useful in making decisions about end-of-life care, some experts recommend:
   a. Leaving end-of-life decisions to other adult family members.
   b. Appointing a healthcare proxy who will decide for the patient should he or she no longer be able to make sound decisions.
   c. Allowing the patient’s primary care physician to decide what is best for the patient.
   d. Waiting until the diagnosis of a serious illness to make difficult ethical decisions about patient care.

12. Do-not-attempt-resuscitation (DNAR) orders are written:
   a. By a physician or nurse when the patient’s family fails to do so.
   b. In the patient’s chart, or the orders can be ignored.
   c. For easy access to all healthcare practitioners in the event of an emergency.
   d. In order to permit any patient to die.

13. By forgoing artificial nutrition and hydration at the end of life, the patient:
   a. Experiences considerable physical and emotional trauma.
   b. Suffers more due to increased hunger and thirst.
   c. Develops pleural effusions.
   d. Increases his or her body’s production of endorphins.

14. In cultures that value protecting a patient with a serious illness from bad news, healthcare decisions for the patient can be:
   a. Referred to the healthcare facility’s ethics body.
   b. Left unspoken at the discretion of the patient’s physician.
   c. Made by promotores from a community agency.
   d. Made in collaboration between the patient’s family and physician.

15. Which is a true statement about pain management?
   a. Healthcare facilities are not required to manage the pain of all patients.
   b. Over 90% of nursing home residents who have advanced cancer pain receive effective treatment.
   c. When pain is relieved, symptoms such as depression, diminished appetite, and impaired sleep may disappear.
   d. At the end of life, it is important to protect patients from drug addiction.
16. When a patient is unable to swallow oral medication, which other route of administration should be offered first?
   a. Intramuscular injection
   b. Subcutaneous injection
   c. Intravenous delivery
   d. Transdermal

17. Which primary therapies are used to treat the shortness of breath that is common among dying patients?
   a. Nonsteroidal anti-inflammatory drugs and acupuncture
   b. Guided imagery, glucosamine, and sponge baths
   c. Oxygen, opioids, and anti-anxiety medications
   d. Inhaled corticosteroids, antibiotics, and yoga

18. The risk factors for delirium include:
   a. Sleep deprivation and visual or hearing impairments.
   b. Vomiting and constipation.
   c. Seizures and depression.
   d. Patient immobility and rheumatoid arthritis.

19. A patient with a terminal illness most commonly expresses a fear of:
   a. Starvation.
   b. Disfigurement.
   c. Pain.
   d. Dying in the presence of family members.

20. The experience of grief is a universal response that is:
   a. Both individual and unpredictable.
   b. Private and best processed internally.
   c. Experienced in the same way in each culture.
   d. Described as occurring in consistent, sequential stages.

21. Bereavement is defined as:
   a. The time period that is approximately six months before a loved one’s death.
   b. The collection of emotions, attitudes, and behaviors faced by a person facing death.
   c. A feeling of desolation following deprivation of a loved one through death.
   d. An experience of anticipatory grief.
22. The U.S. Food and Drug Administration issued a safety announcement that drugs used to treat anemia in patients with cancer can cause:
   a. Risk of seizures.
   b. Mental disorders such as depression.
   c. Increased risk of tumor growth.
   d. Decreased appetite.

23. A patient who is receiving tube feedings in the late stages of dementia has:
   a. A decreased prevalence of pressure ulcers.
   b. A reduced volume of acute diarrhea.
   c. An improved survival time.
   d. An increased risk of lung infection.

24. Which is a true statement about issues facing a patient who is living with advanced HIV infection?
   a. The disease trajectory has become much more predictable due to the latest treatment options.
   b. The patient’s psychosocial concerns are no different from those of patients with other terminal illnesses.
   c. The patient may become socially isolated and lack a support system.
   d. The patient most likely has a strong traditional support system of friends and family members.

25. Which is a true statement regarding end-of-life issues among children?
   a. Infants require less pain management since they are not as sensitive to pain as adults.
   b. Between the ages of 2 to 6, children typically come to understand death as final and irreversible.
   c. Very young children are not usually aware they are dying.
   d. Parents have legal responsibility for decisions about a child’s treatment.

26. The parents of a dying child should:
   a. Talk with them about what they are feeling and what they understand.
   b. Keep the diagnosis from them.
   c. Encourage them not to go to school.
   d. Make all of the end-of-life decisions for their child.
27. When caring for veterans who are dying, health professionals are aware that:
   a. Hospice care is not a provided benefit by the Department of Veterans Affairs.
   b. A veteran may be unwilling to admit being in pain.
   c. A veteran usually has strong family support.
   d. Enlisted and drafted veterans have the same experiences as one another.

28. A sign of imminent death in patients is:
   a. An increased production of urine.
   b. A turning away from a light source.
   c. Quiet and regular breath sounds.
   d. Decreased socialization and withdrawal.

29. Postmortem care includes:
   a. Adapting practices according to the patient’s religion and culture.
   b. Elevating the patient’s legs with pillows in order to prevent facial discoloration.
   c. Allowing the family only a brief visit with the patient’s body to avoid upset feelings.
   d. Performing an autopsy to reveal possible errors in the patient’s clinical diagnosis.

30. An online support group for a bereaved family member is recommended to:
   a. Discourage family sharing.
   b. Enhance in-person therapy.
   c. Predict suicidal behavior.
   d. Replace medical therapy.