

West Virginia: End of Life Care

4.5 contact hours: \$19

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Course Summary: Reviews end-of-life issues including the Patient Self-Determination Act, advance care planning, palliative and hospice care, and special needs of children. Looks at treatment options for those at the end of life and support measures for those experiencing bereavement, mourning, and grief.

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Criteria for Successful Completion: 80% or higher on the post test, a completed evaluation form, and payment where required. No partial credit will be awarded.

This course will be reviewed every two years. It will be updated or discontinued on September 1, 2013.

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Instructional Level: Intermediate

Content Focus: Category 1 - Domain of OT, Client Factors

Category 2 - Occupational Therapy Process, Outcomes

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Course Objectives

When you finish this course, you will be able to:

- List the main components of the Patient Self-Determination Act.
- Compare and contrast palliative and hospice care.
- Outline the main issues associated with end-of-life care in children.
- Explain the process of advance care planning.
- Identify treatment options for common symptoms seen at the end of life.
- Discuss the importance of supporting bereavement, mourning, and grief.

Introduction

Improvements in medical science and healthcare have gradually changed the nature of dying. Death is no longer predominately the sudden result of infection or injury but is now more likely to occur slowly, in old age, and at the end of a period of life-limiting or chronic illness.

National Institutes of Health, 2004a

Only a century ago, death was common at every age and dying usually quickly followed the onset of disease or injury. Today, public health measures and modern medical care prevent or cure many previously fatal illnesses or injuries, allowing most Americans to live into old age (AHRQ, 2004a).

The life expectancy of the American people has reached an all-time high, with a 30-year increase since the dawn of the twentieth century. With our longer lives there is an increase in the number of people living with, and dying from, chronic debilitating diseases such as heart disease, cancer, stroke, and chronic obstructive pulmonary disease (NIH, 2000).

For the relatively healthy, a care system focused on curing acute intermittent illness is adequate. However, because many Americans today live their last years with chronic illness, the end of life is no longer a brief, well-defined event, but often a prolonged, uncertain period of difficulty. For these people neither prevention nor cure is ordinarily possible. Instead, these patients and their families have other concerns, including management of pain and other symptoms and the coordination of care among multiple providers and settings. Advancing age also dramatically increases the likelihood of disability and further declines in functioning, recurrent hospitalization, and ultimate institutionalization (AHRQ, 2004a).

In addition to the chronically ill elders, there are other groups who have important end-of-life concerns. Examples extend across the lifespan and include neonates in intensive care units, children with AIDS, teens with cancer, and young adults with degenerative diseases. With the increased availability of technologies and treatments that can be used to prolong life—and, in some cases, death—it is difficult to define when these technologies and treatments shift from lifesaving interventions to burdensome and futile procedures that negatively impact quality of life. When these interventions become futile, the individuals' families and significant others may be involved in a difficult period of decision-making about how much aggressive treatment to try and when to stop. There is widespread fear that the only alternative to aggressive treatment is abandonment and suffering (NIH, 2000).

For many Americans, end-of-life care is fragmented, painful, and emotionally distressing, with unnecessary transitions between healthcare institutions, community-based organizations, and home care. Although death itself is ultimately not preventable, much of the suffering that may accompany the dying process is amenable to intervention to ensure that the last months and days of life are lived as fully as possible and with dignity and choice (NIH, 2000).

End of Life Care in West Virginia

In the late 1990s, end-of-life (EOL) care for West Virginia's citizens was being negatively impacted by conflicting state laws on patient decision making, low referrals to hospice (below the national average), and the fact that nearly half of all deaths took place in hospitals, incurring the highest possible costs. To deal with this problem, in 1998 thirty-seven people from more than fifteen separate institutions formed the West Virginia Initiative to Improve End-of-Life Care (RWJF, 2008).

West Virginia Initiative to Improve EOL Care

During 1999–2002, the initiative received two grants as part of the Robert Wood Johnson Foundation's (RWJF) national program, Community-State Partnerships to Improve End-of-Life Care. The first grant funded a survey among healthcare professionals (most of whom rated care in the state as "fair to poor"), ten community and eight senior center meetings to obtain citizen input, and ultimately "a plan to improve end-of-life care in West Virginia." The second grant helped fund three years of work to implement that plan (RWJF, 2008).

During those three years (2000–2002) the West Virginia Initiative to Improve End-of-Life Care worked to effect policy and implement programs that would help both physicians and patients—help patients define their wishes for care and physicians to comply with those wishes. The initiative helped establish and fund five palliative care teams (at one hospice and four hospitals), one of which helped facilitate a 25% increase in referrals from its hospital system to hospice care; established the West Virginia Palliative Care Network; provided information to legislators regarding professional continuing education for healthcare professionals; and helped establish the Physician Orders For Scope of Treatment (POST) system (RWJF, 2008; WVCEOLC, 2011).

In 2000 an important step took place when the initiative issued the Joint Policy Statement on Pain Management at the End of Life, which represented a cooperative effort by West Virginia's professional medical licensing boards intended to reduce professional uncertainty and improve pain management for patients (WVCEOLC, 2011).

In 2002, as an evolution of the initiative, the West Virginia Center for End-of-Life Care was established with support from the state legislature. Today it spearheads the coordination of EOL information and training for healthcare providers, the general public, and legislators. Its mission is to "provide[s] assistance to West Virginians so that at the end of life they know what medical treatments they want and their wishes are respected." Because EOL care is intimately connected to ethical considerations, the center has always had a close relationship with the Center for Health Ethics and Law at West Virginia University, which coordinates the WV Network of Ethics Committees. These three entities coordinate information, resources, and forms for patients, families, healthcare providers, and institutions, and facilitate the formation of local ethics committees (WVCEOLC website).

One of West Virginia's Healthy People 2010 goals was to raise the percentage of the state's citizens with advance directives from 34% (in 2000) to 50%. Today 49% of West Virginians have completed some form of advance directive—the highest percentage in the United States. In early 2011, the West Virginia Center for End-of-Life Care rolled out the eDirective Registry, which allows online registration of advance directive information, which can then be quickly accessed by healthcare providers in times of need. It is one of only a few such programs in the country (WVCEOLC website; Murray/WSJ, 2010).

Raising awareness of and attention to EOL issues remains a continuing challenge in West Virginia, as it is everywhere. These are often difficult issues for patients, families, and healthcare providers to deal with, and most physicians receive little to no training for dealing with them. Efforts to educate patients, families, and healthcare providers in West Virginia include workshops, community meetings, printed materials, and many kinds of online resources. Two recent programs of note are an hour-long documentary produced by West Virginia Public Broadcasting, which aired in December 2010 (it is available on the WVPBS website), and the play *Mercy Machine*, which debuted in April 2011 in Morgantown. Written by a WVU graduate and experienced healthcare provider, the play follows the events and ethical concerns of a dying patient and her nurse practitioner. The play debuted in conjunction with National Healthcare Decisions Day and one performance was preceded by a community discussion and distribution of advance directive forms (Smith, 2011; WVPBS, 2010).

Legislative Overview

In West Virginia, EOL issues of importance to both patients and healthcare providers first received legislative attention in 1984 when the state legislature enacted the Natural Death Act, to allow persons over 18 to withhold or end life-sustaining procedures through use of a "declaration," which was amended in 1991 to be a "living will." Also in 1984 the legislature passed legislation providing guidelines for licensing hospice facilities. In the 1990s several more important pieces of legislation were passed, including the Medical Power of Attorney Act, the Health Care Surrogate Act, the Do Not Resuscitate Act, and the Management of Intractable Pain Act (WVCEOLC, 2011).

In 2000 the legislature passed the West Virginia Health Care Decisions Act, which replaced and combined the Natural Death Act, Medical Power of Attorney Act, and Health Care Surrogate Act. The new act kept the provisions of the other three but modernized the language and established a process to resolve conflicts among different advance directives and between surrogates and physicians. In 2001 the legislature established a requirement that medical professionals present proof of completing a two-hour continuing-education course in EOL care, including pain management, for each professional license renewal. In 2005 this was amended to be a one-time course requirement (WVCEOLC, 2011).

In 2002 two important amendments to legislation were passed. First, the legislature amended the Management of Intractable Pain Act to allow policy or position statements to be considered “accepted guidelines” and provided legal protections for doctors following such guidelines. Second, the Health Care Decisions Act was amended to include the use of Physician Orders For Scope of Treatment (POST) forms and provided immunity for healthcare providers who rely on POST forms in providing care. Amendments in 2007 incorporated the combined Living Will/Medical Power of Attorney form into the act (WVCEOLC, 2011; 2007). Finally, in 2009, H.B. 2839, the Management of Pain Act, amended and re-enacted certain portions of relevant state code, including removing the word *intractable* from the definition of pain. The different types of advance directives will be discussed later in this course and complete wording of all laws are available through the website of the West Virginia Center for End-of-Life Care.

Defining End of Life

All of us follow an arc of life that, as time goes on, includes illnesses, decreasing functionality, and ultimately death. The term **end of life** describes a process that includes physical, emotional, spiritual, and financial transitions that accompany aging. These personal transitions are often hindered by a lack of continuity among caregivers, challenges to social support networks, unshared clinical information, and multiple physical locations for care. In addition, family members experience role transitions, stress, and ultimately bereavement (NIH, 2004b).

Although the EOL process cannot be defined precisely, there is evidence to support the following components (NIH, 2004):

- The presence of a chronic disease or symptoms or functional impairments that persist but may also fluctuate; and
- Symptoms or impairments resulting from the underlying irreversible disease that require formal (paid or professional) or informal (unpaid) care and can lead to death.

Older age and frailty may exacerbate life-threatening illnesses but there is not sufficient evidence to include them among the components of end of life (NIH, 2004b).

Population Trends and Statistics

Modern medications and treatments have allowed many Americans to live longer lives, though often with serious chronic conditions. Among chronic conditions that typically worsen and eventually cause death are cancer; chronic heart, lung, liver, or renal disease; dementia; and stroke. Nine-tenths of those insured by Medicare (ie, over 65) live with one or more of these conditions in the year prior to their death (National Library of Medicine, 2004a).

Most Americans will have a substantial period of serious illness before dying, with onset months or years before death. Half of Americans who live to age 85 have major memory loss in their final years and the growing size of the aging population suggests that many Americans will face chronic illness and impairment as the baby boomers grow old (NLM, 2004a).

More than one-third of lifetime expenditures are still ahead of a person who is alive at age 85, and more than half are still ahead of a person at age 65. The length of time a person lives is relatively unimportant in predicting total costs, and lifetime medical expenditures are similar for those who start retirement healthier and those who start more disabled, because even healthier persons eventually reach the disabled state at the end of life, and that period of time is very costly. About 30% of lifetime Medicare expenditures are used during the last year of life (NLM, 2004a).

Aging in America

- More than 75% of Americans now live past the age of 65.
- By 2050, life expectancy for women is predicted to be 84 years and the life expectancy for men will be 80 years.
- By 2030, the population over 80 years of age will increase from approximately 3% to more than 5% of the population, numbering roughly 19 million.
- Eighty-three percent of Americans now die while covered by Medicare.
- Nine-tenths of those insured by Medicare live with one or more chronic conditions in the year before death.
- Forty million people (15% of the adult U.S. population) are limited in activities from chronic health conditions.
- One-twelfth of these people have severe cognitive impairments, one-third have difficulty walking, and one-fifth have impaired vision.
- After age 85, only 1 person in 20 reports being fully mobile.
- About 30% of lifetime Medicare expenditures are used during the last year of life.

Source: NLM, 2004a.

The Patient Self-Determination Act

End-of-life care refers to the medical and psychosocial care given in the advance or terminal stages of illness. Advance directives are legal documents—a living will, durable power of attorney, healthcare proxy, and do-not-resuscitate orders—that allow people to convey their decisions about EOL care while they are still capable of making decisions. Advance directives provide a way for patients to communicate their wishes to family, friends, and healthcare professionals so as to avoid confusion later on (NCI, 2000).

On December 1, 1991, the federal Patient Self-Determination Act (PSDA) took effect across the United States, requiring healthcare institution to ask all adults admitted as inpatients whether they have an advance directive and to inform them of their right to refuse treatment. Institutions failing to meet the federal standards risk losing Medicare and Medicaid funds. The law has three primary purposes (NLM, 2008):

- To educate the public about state laws governing the refusal, withholding, and withdrawal of treatment at the end of life;

- To encourage wider use of advance directives to prevent the uncertainty among doctors and family members that often leads to prolonged treatment of the dying, and in some cases to lengthy court battles; and
- To reduce the costs of treatment at the end of life by reducing unwanted and unnecessary intervention and the perceived need for defensive medicine.

The PSDA and advance directive statutes assume that people want, need, and can appreciate information about medical technologic intervention. It further assumes that health professionals and institutions will respect those decisions (NLM, 2008).

Discussing and writing advance directives should not be a single event but an ongoing process, so that the directives can be modified as a patient's situation changes. It is also important to know that advance directives can be changed by the patient at any time. Advance directives will be discussed further later in this course.

Palliative and Hospice Care

Hospice and palliative care involve a team-oriented approach for patients nearing the end of life that includes expert medical care, pain management, and emotional and spiritual support. The team-oriented care is tailored to the person's needs and wishes while providing support to the person's loved ones. **Palliative care** manages the needs of patients who have progressive, incurable illness while **hospice care** focuses on patients in the last six months of their lives (Caring Connections, n.d., used with permission).

The word *hospice* comes from the same root as the word "hospitality," and in medieval times it referred to a place for travelers to rest. The first modern hospice, St. Christopher's Hospice, was established in 1967 by English physician Cicely Saunders in London (National Palliative and Hospice Care Organization, 2010).

Saunders originally worked with suffering and dying soldiers as a nursing student at the end of World War II, and she came to believe that much more could be done to care for people nearing the end of their lives. She eventually earned degrees in both medicine and social work. Her research found two special needs of the dying that were not being met by conventional treatment: pain control and concern for the patient as a whole human being (Seasons Hospice and Palliative Care, n.d.).

The basic tenets of hospice developed by Saunders included the belief that death is the natural conclusion of life. She advocated the delivery of care by an interdisciplinary healthcare team with an emphasis on pain management, home care services, and counseling for the patient and family. These concepts became the cornerstone for hospices around the world (Wexler and Frey, 2004). Influenced by the work of Cicely Saunders, Florence Wald of Yale University established the first modern hospice in the United States in Branford, Connecticut in 1974 (National Hospice Foundation, 2010).

Elizabeth Kübler-Ross wrote *On Death and Dying* in 1969, a book that advocated home care rather than institutional care for the dying, and importantly identified the stages of grief that many people go through at the end of life. Kübler-Ross testified before the U.S. Senate Special Committee on Aging in 1972, and in 1982 a Medicare hospice benefit was created (NHPCO, 2010).

Palliative Care

[Except where cited, the material in this section is from StopPain.org.]

According to the World Health Organization (WHO), "Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain and other symptoms, and of psychological, social, and spiritual problems, is paramount. The goal of palliative care is the achievement of the best possible quality of life for patients and their families."

Palliative care is an interdisciplinary approach to care that focuses on management of the physical, psychological, social, and spiritual needs of patients who have progressive incurable illnesses. Palliative care can be given at any time throughout the course of an illness, along with curative and aggressive treatments. It includes a number of interventions that are intended to maintain the quality of life and ease the suffering of both the patient and their family. As death approaches, palliative care must intensify and ensure that comfort is a priority and practical needs are addressed (NCI, 2010c).

The goal of palliative care is to improve the patient's and the family's quality of life by preventing and relieving suffering. This includes treating physical symptoms such as pain, and dealing with emotional, social, and spiritual concerns. When palliative treatment is given at the end of life, care is taken to make sure the patient's wishes about treatments are followed (NCI, 2010c).

Palliative care is an approach to patient care that should be routinely integrated with life-prolonging therapies. It is a growing practice specialty for physicians, nurses, social workers, chaplains, and others, who typically work in teams. It is usually needed when the disease is advanced, life expectancy is short, and problems become complex and more urgent. These problems are most often related to uncontrolled symptoms, conflicted or unclear goals of care, distress related to the process of dying, and increasing family burden.

The definition of palliative care has much in common with hospice, but in the United States palliative care is evolving in a way that goes well beyond the American version of hospice. Palliative care aims to address the physical, psychosocial, and spiritual concerns that contribute to both the quality of life and quality of dying for patients with life-threatening illnesses at any phase of the disease. Although the focus intensifies at the end of life, the core issues of comfort and function are important throughout the course of the disease.

For the many patients with incurable and progressive diseases who are undergoing active life-prolonging therapies and have life expectancies that potentially extend to years, palliative care includes symptom management, therapy aimed at restoring function, practical support, and psychological interventions. At all stages of the disease, effective palliative care increases the likelihood that the patient will cope adequately with the rigors of therapy and maintain a satisfying level of physical and psychosocial functioning.

For the dying patient, optimal palliative care addresses the traditional concerns of the hospice movement. Preparation of the patient and family for the inevitability of dying and the comfort of the patient are often the biggest challenges during this time. This preparation may have to address a broad range of psychological, social, family, and spiritual concerns.

All patients with progressive incurable diseases, and the families of these patients, need ongoing palliative care throughout the course of the disease, from the time of diagnosis until the final outcome. During much of this period, palliative care will focus on the provision of medical and nonmedical interventions intended to help the patient and family maintain the best quality of life possible as the patient lives with the disease. As the disease becomes more advanced, palliative care begins to focus on maintaining patient comfort and ensuring that other needs are addressed. Support of the family during this time, including bereavement support, is essential.

The role of palliative care in EOL situations has been an important consideration in West Virginia. The original work of the West Virginia Initiative to Improve End-of-Life Care helped establish and fund palliative care teams at four hospitals and a hospice, and team members established the West Virginia Palliative Care Network in 2001, which, as an element of the West Virginia Initiative for End-of-Life Care, continues to provide training and assistance (RWJF, 2008; WVCEOLC website).

Clinical Practice Guidelines for Quality Palliative Care

[These guidelines appear with permission of the National Guideline Clearinghouse, 2009.]

The guidelines for quality palliative care were developed by the National Consensus Project for Quality Palliative Care in 2004 and updated in 2009. These guidelines represent a consensus of the major palliative care organizations and leaders in the United States and are based both on the available scientific evidence and expert professional opinion.

The guidelines were developed to:

- Describe what constitutes comprehensive high-quality palliative care services, and serve as a resource for practitioners addressing the palliative care needs of patients and families in primary treatment settings
- Build national consensus around the definition, philosophy, and principles of palliative care in order to achieve quality by the systematic evaluation of care, providing criteria for outcome data, and developing validated instruments

The guidelines target patients of all ages who are living with a persistent or recurring condition that adversely affects their daily functioning or will reduce life expectancy, including the following groups:

- Children and adults with congenital injuries or conditions requiring life-sustaining treatments and/or long-term care by others for support of activities of daily living.
- Persons of any age with acute, serious, and life-threatening illnesses (such as severe trauma, leukemia, or acute stroke), where cure or reversibility is a realistic goal, but the conditions themselves and their treatments pose significant burdens.
- Persons living with progressive chronic conditions (such as peripheral vascular disease, malignancies, chronic renal or liver failure, stroke with significant functional impairment, advanced heart or lung disease, frailty, neurodegenerative disorders, and dementia).

- Persons living with chronic and life-limiting injuries from accidents or other forms of trauma.
- Seriously and terminally ill patients (such as persons living with end-stage dementia, terminal cancer, or severe disabling stroke), who are unlikely to recover or stabilize, and for whom intensive palliative care is the predominant focus and goal of care for the remainder of their lives.
- Family members or other individuals who provide support and with whom the patient has a significant relationship.

Excellence in palliative care requires expertise in the clinical management of problems in multiple domains. The palliative care guidelines describe eight domains.

1. **The structure and processes of care should:**

- Establish a plan of care based on a comprehensive interdisciplinary assessment of the patient and family.
- Identify patient and family values, goals, and needs.
- Provide services to the patient and family consistent with the plan of care.
- Assure appropriate training and supervision of volunteers and staff.
- Maintain education, training, and quality assessment of the interdisciplinary team.

2. **Physical aspects of care should:**

- Ensure the management of pain, symptoms, and side effects.
- Provide referral to specialists, as appropriate.
- Provide patient and family education about the disease process and its management.

3. **Psychological and psychiatric aspects of care should:**

- Ensure regular, ongoing assessment of psychological and psychiatric reactions.
- Provide pharmacologic and non-pharmacologic management of psychological/psychiatric distress.
- Refer to specialists, as appropriate.
- Provide grief and bereavement programs to patients and families.

4. **Social aspects of care should:**

- Assess the social needs of patients and families.
- Develop a care plan responsive to social needs.
- Refer to appropriate social services.

5. **Spiritual, religious, and existential aspects of care should:**

- Provide ongoing spiritual, religious, and existential assessments.
- Facilitate religious and spiritual needs of patients and families, including access to clergy.

6. Cultural aspects of care should:

- Assess and provide for culture-specific needs of patients and families.
- Ensure recruitment and hiring practices that reflect the cultural diversity of the community.

7. Care of the imminently dying patient should:

- Recognize and communicate signs and symptoms of impending death and provide care that is appropriate to the patient and family.

8. Ethical and legal aspects of care should:

- Consider the legal and ethical aspects of medical decision-making, including advance care directives.

Hospice Care

[This section on hospice is taken largely from Caring Connections, and is used with permission.]

Hospice care is based on the premise that each of us has the right to die pain-free and with dignity, and that our loved ones should receive the necessary support to allow us to do so.

Caring Connections, n.d.

Hospice care is for people who are nearing the end of their lives, usually with an expected survival of six months or less. Its goal is to improve the quality of life that remains by focusing on providing care for the patient and the family rather than attempting to cure the disease. Hospice is designed to relieve or decrease pain or other symptoms, and provide as much quality time as possible with family and friends while meeting the physical, emotional, and spiritual needs of the dying individual (MayoClinic.com, 2010).

The goal of all hospice care is palliation, or making the patient as comfortable as possible—not dulled by social isolation, drugs, or heroic life-saving efforts. It:

- Focuses on caring, not curing.
- Is usually provided in the person's home, but may also be provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities.
- Is available to patients of any age, religion, race, or illness.
- Is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations.

The Hospice Team

Hospice care is a family-centered approach. The hospice care team includes doctors, nurses, home health aides, social workers, chaplains, counselors, and trained volunteers who work together to address the dying person's physical, emotional, and spiritual needs. The goal is to help keep the person as pain-free as possible, with loved ones nearby until death. The hospice team develops a care plan that meets each person's individual needs for pain management and symptom control.

The team usually consists of:

- Clergy or other counselors
- Home health aides
- Hospice physician (or medical director)
- Nurses
- Social workers
- Trained volunteers
- Speech, physical, and occupational therapists, if needed
- The person's personal physician may also be included.

It is important to have a physician involved to ensure quality hospice care. The patient can usually choose to have their personal doctor work with the hospice medical director to coordinate medical care, especially when symptoms are difficult to manage. The hospice medical director is also available to answer questions the person or loved ones may have regarding hospice medical care.

In many cases, family members or loved ones are the dying person's primary caregivers and have their own special needs for support. As a relationship with the hospice begins, hospice staff will want to know how best to support the person and family during this time.

Among its major responsibilities, the interdisciplinary hospice team:

- Manages the person's pain and symptoms
- Provides emotional support
- Provides needed medications, medical supplies, and equipment
- Coaches loved ones on how to care for the person
- Delivers special services like speech and physical therapy when needed
- Makes short-term inpatient care available when pain or symptoms become too difficult to manage at home, or the caregiver needs respite time
- Provides grief support to surviving loved ones and friends

Support can include conversations with the person and family members, teaching caregiving skills, prayer, telephone calls to loved ones including family members who live at a distance, and companionship and help from volunteers.

Counseling and grief support for the dying person and their loved ones are important parts of hospice care. After the person's death, bereavement support is offered to families for at least one year. These services can include telephone calls, visits, written materials about grieving, and support groups. Individual counseling may be offered by the hospice, or the hospice may make a referral to a community resource.

Paying for Hospice

For some people, hospice expenses are paid by health insurance plans (either group policies offered by employers or individual policies). Information about the types of medical costs covered by a particular policy is available from an employee's personnel office, a hospital or hospice social worker, or an insurance company. Medical costs that are not covered by insurance are sometimes tax-deductible (NCI, 2006).

Medicare—a health insurance program for elders and the disabled that is administered by the Centers for Medicare & Medicaid Services (CMS) of the federal government—provides payment for hospice care. When a patient receives services from a Medicare-certified hospice, Medicare insurance provides substantial coverage, even for some services that would not be covered outside a hospice program (NCI, 2006).

The Medicare hospice benefit was initiated in 1983 and is covered under Medicare Part A (hospital insurance). Medicare beneficiaries who choose hospice care receive a full range of medical and support services for their life-limiting illness. Hospice care also supports the family and loved ones of the dying person through a variety of services (Caring Connections, n.d.).

More than 90% of hospices in the United States are certified by Medicare. Eighty percent of people who use hospice care are over the age of 65, and are thus entitled to the services offered by the Medicare hospice benefit. This benefit covers virtually all aspects of hospice care with little expense to the person or family. In addition, most private health plans plus Medicaid in 47 states and the District of Columbia cover hospice services (Caring Connections, n.d.).

Medicaid, a federal program that is part of CMS and is administered by each state, is designed for patients who need financial assistance for medical expenses. Information about coverage is available from state welfare offices, state public health departments, state social services agencies, or the state Medicaid office. In addition, local civic, charitable, or religious organizations may be able to help patients and their families with hospice expenses. Hospice will also work with the person and their family to ensure needed services can be provided (NCI, 2006).

If a patient's health improves or their illness goes into remission, their physician may decide hospice is no longer needed. The patient may also choose to terminate hospice services at any time. When hospice services are stopped, the patient will receive the type of Medicare coverage received before hospice care. If patients are eligible, they may go back to hospice care at any time (Caring Connections, n.d.).

Eligibility for Medicare Hospice Benefits

In order to be eligible for Medicare hospice benefits, a patient must:

- Be eligible for Medicare Part A (Hospital Insurance).
- Be certified by their doctor and the hospice medical director to have a life-limiting illness that, if the disease runs its normal course, may result in death in six months or less.
- Sign a statement choosing hospice care instead of routine Medicare-covered benefits.
- Receive care from a Medicare-approved hospice program. (Caring Connections, n.d.)

Medicare will continue to pay covered benefits for any health needs that are not related to the life-limiting illness.

Medicare Coverage

[This section is taken from Caring Connections with permission.]

Medicare defines a set of core services that hospices are required to provide to each person, regardless of that person's insurance. Medicare covers these hospice services and pays nearly all of their costs:

- Doctor services
- Nursing care
- Medical equipment (like wheelchairs or walkers)
- Medical supplies (like bandages and catheters)
- Drugs for symptom control and pain relief
- Short-term care in the hospital, including respite and inpatient for pain and symptom management
- Home health aide and homemaker services
- Physical and occupational therapy
- Speech therapy
- Social work services
- Dietary counseling
- Grief support to the patient and their family

The hospice patient will have to pay part of the cost for outpatient drugs and inpatient respite care.

The Medicare Hospice Benefit does not cover:

- Treatment intended to cure the illness
 - Patients will receive comfort care to help manage symptoms related to their illness. Comfort care includes medications for symptom control and pain relief, physical care, counseling, and other hospice services.
- Medications not directly related to the hospice diagnosis
 - Hospice team members will consult with the hospice physician and will inform the person and their family which drugs and/or medications are covered and which ones are not covered under the Medicare hospice benefit.
- Care from another provider that is the same care provided by hospice
 - All care received for the life-limiting illness must be given by the hospice team. The patient cannot get the same type of care from a different provider unless the hospice provider is changed.
- Nursing home room and board
 - Room and board are not covered by Medicare. Although a person may receive hospice services wherever they live, even in a nursing home, the Medicare hospice benefit does not pay for nursing home room and board.

Breaking Bad News

Informing someone of a life-threatening diagnosis is a heart wrenching and difficult task. This is called “breaking bad news” and can be defined as any information that adversely and seriously affects an individual's view of his or her future (The Oncologist, 2000).

Breaking bad news is a complex task that requires good communication skills. Telling a patient that they have cancer has been described as “hitting the patient over the head” or “dropping a bomb.” The healthcare provider must be able to deal with patient’s emotional reactions and involve the patient in decision-making. The clinician must deal with the stress created by patients' expectations for a cure, the involvement of multiple family members, and the dilemma of how to give hope when the situation is bleak (NIA, 2008a).

This complex interaction can sometimes create serious miscommunications and cause misunderstanding about the prognosis of the illness or purpose of care. Poor communication also makes it difficult to involve the patient in treatment planning or to understand the patient’s expectations of treatment, but tested strategies can ease the process (The Oncologist, 2000).

Knowing how to communicate bad news can make the process more bearable for both patients and the healthcare providers who must deliver the bad news. The National Institutes of Health recommends the following steps (NIA, 2008a):

- Allow enough time, be prepared, and think about what will be said. Gather all information needed before speaking with the patient.
- Find out how much the patient understands and how much the patient wants to know about the prognosis.
 - If a patient's family has reservations about having the patient know the prognosis, you might ask them about their concerns. Legally, the patient has the right to know; however, some elements may be negotiated with the family. If this cannot be resolved, an ethics consultation may be helpful.
- Be straightforward and compassionate.
 - When you are ready to share the bad news, try to be as straightforward as possible, without speaking in a monotone or delivering a monologue. Be positive, but avoid the natural temptation to minimize the seriousness of the diagnosis.
- Give the patient time to react.
 - Establish a plan for the next steps. This may include gathering more information, ordering more tests, or preparing advance directives.
 - Let the patient and family know they will not be abandoned.
 - Give the patient an opportunity to continue the conversation in follow-up appointments or calls. Ask if the patient has more questions or needs help talking with family members or others about the diagnosis.
 - Assess the patient’s level of emotional distress and consider a referral to a mental health provider.

The SPIKES Protocol

[This section is courtesy of *The Oncologist* and is used with permission.]

The task of breaking bad news can be improved by understanding the process involved and approaching it as a stepwise procedure while applying well-established principles of communication and counseling.

The SPIKES Protocol consists of six steps that enable the clinician to fulfill the four most important objectives of the interview:

- Gathering information from the patient
- Transmitting the medical information
- Providing support to the patient
- Eliciting the patient's collaboration in developing a strategy or treatment plan for the future

STEP 1: SETTING UP the Interview

Review the plan for giving the patient bad news and how to respond to the patient's emotional reactions or difficult questions. As the messenger of bad news, you can expect to have negative feelings and to feel frustration or responsibility. However, although bad news may be very sad for the patient, the information may be important in allowing the patient to plan for the future.

There should be as much privacy as possible. Unless there is a semblance of privacy and the setting is conducive to undistracted and focused discussion, the goals of the interview may not be met. Some helpful guidelines are:

- Arrange for as much privacy as possible.
- Involve significant others. Most patients want to have someone else with them, but this should be the patient's choice. When there are many family members, ask the patient to choose one or two family representatives.
- Sit down. Sitting down relaxes the patient and is also a sign the discussion will not be rushed. When you sit, try not to have barriers between you and the patient. If you have recently examined the patient, allow them to dress before the discussion.
- Make a connection with the patient. Maintaining eye contact may be uncomfortable but it is an important way of establishing rapport. Touching the patient on the arm or holding a hand (if the patient is comfortable with this) is another way to accomplish this.
- Manage time constraints and interruptions. Inform the patient of any time constraints you may have or interruptions you expect.

STEP 2: Assessing the Patient's PERCEPTION

Before you tell, ask. Before discussing the medical findings, use open-ended questions to determine how the patient perceives the medical situation—what it is and whether it is serious or not. Misinformation can then be corrected and the bad news can be tailored to what the patient understands. It can also accomplish the important task of determining if the patient is engaging in any variation of illness denial: wishful thinking, omission of essential but unfavorable medical details of the illness, or unrealistic expectations of treatment.

STEP 3: Obtaining the Patient's INVITATION

While a majority of patients express a desire for full information about their diagnosis, prognosis, and details of their illness, some patients do not. When a clinician hears a patient express a desire for information, it may lessen the anxiety associated with divulging the bad news. However, shunning information is a valid psychological coping mechanism and may be more likely as the illness becomes more severe.

Discussing information disclosure at the time of ordering tests can cue the physician to plan the next discussion with the patient. Examples of questions to ask the patient: How would you like me to give the information about the test results? Would you like me to give you all the information or sketch out the results and spend more time discussing the treatment plan?

If patients do not want to know details, offer to answer any questions they may have in the future or to talk to a relative or friend.

STEP 4: Giving KNOWLEDGE and Information to the Patient

Warning the patient that bad news is coming may lessen the shock that can follow the disclosure and may facilitate information processing. Examples of phrases that can be used include, "Unfortunately, I've got some bad news to tell you" or "I'm sorry to tell you that...."

Giving medical facts may be improved by a few simple guidelines:

- Start at the level of comprehension and vocabulary of the patient.
- Try to use nontechnical words such as *spread* instead of "metastasized" and *sample of tissue* instead of "biopsy."
- Avoid excessive bluntness (eg, "You have very bad cancer and unless you get treatment immediately you are going to die") as it is likely to leave the patient isolated and later angry, with a tendency to blame the messenger of the bad news.
- Give information in small chunks and check periodically as to the patient's understanding.
- When the prognosis is poor, avoid using phrases such as "There is nothing more we can do for you." This attitude is inconsistent with the fact that patients often have other important therapeutic goals such as good pain control and symptom relief.

STEP 5: Addressing the Patient's Emotions with EMPATHIC Responses

Responding to the patient's emotions is one of the most difficult challenges of breaking bad news. Patients' emotional reactions may vary from silence to disbelief, crying, denial, or anger.

When patients get bad news, their emotional reaction is often an expression of shock, isolation, and grief. In this situation you can offer support and solidarity to the patient by making an empathic response. An empathic response consists of four steps:

- Observe for any emotion on the part of the patient. This may be tearfulness, a look of sadness, silence, or shock.
- Identify the emotion experienced by the patient. If a patient appears sad but is silent, use open questions as to what they are thinking or feeling.
- Identify the reason for the emotion. This is usually connected to the bad news. If you are not sure, ask the patient.

- After you have given the patient a brief period of time to express feelings, let the patient know that you understand the reason for the feelings.

Until an emotion is cleared, it will be difficult to go on to discuss other issues. If the emotion does not diminish shortly, it is helpful to continue to make empathic responses until the patient becomes calm. Clinicians can also use empathic responses to acknowledge their own sadness or other emotions ("I wish the news were better").

When emotions are not clearly expressed, such as when the patient is silent, ask an exploratory question before making an empathic response. When emotions are subtle or indirectly expressed, or disguised in thinly veiled disappointment or anger ("I guess this means I'll have to suffer through chemotherapy again") you can still use an empathic response ("I can see that this is upsetting news for you").

Combining empathic, exploratory, and validating statements is one of the most powerful ways of providing support. It reduces the patient's isolation, expresses solidarity, and validates the patient's feelings or thoughts as normal and to be expected.

STEP 6: STRATEGY and Summary

Patients who have a clear plan for the future are less likely to feel anxious and uncertain. Before discussing a treatment plan, it is important to ask patients if they are ready for such a discussion. Presenting treatment options to patients when they are available is not only a legal mandate in some cases, but it will establish the perception that the healthcare provider regards their wishes as important. Checking the patient's understanding of the discussion can prevent the tendency of patients to overestimate the efficacy or misunderstand the purpose of treatment.

Special Populations

Children

More than 50,000 children die each year in the United States, but most of these children do not receive hospice care. Only 10% to 20% of dying children currently receive hospice services, and the same number of children who have life-threatening illness receive palliative care (Children's Hospice & Palliative Care Coalition, 2007).

Like adult palliative and hospice care, pediatric palliative care is a multidisciplinary and family-centered approach to the care of children living with life-threatening illnesses. Using professionals from the fields of medicine, nursing, social work, nutritional services, and other areas, the goal is to relieve suffering and improve quality of life for both the patient and the family. This care can be given at the same time as curative treatments, or may be given after curative treatments end (Children's Hospice, 2007).

The care of seriously ill or dying children is different from adult care in many ways. Children are not small adults and treatment and supportive care require different approaches. Medications that are used for adult supportive care may be contraindicated in children because of toxicities associated with specific periods of childhood development (NCI, 2010e).

When adults are suffering from a life-threatening illness, the impact of treatment often focuses on one or two key people in the patient's life. The treatment of a child with a life-threatening illness occurs in the context of an entire family. The effects may be felt by many people, including one or both parents, one or more siblings who are themselves children or adolescents, grandparents, aunts and uncles, teachers, friends, and other individuals who may be directly involved in the care or life of the child. Parents must be partners with healthcare providers in decisions about their child's EOL care but are often not prepared to make a choice between comfort and curative treatments (NCI, 2010e).

Because children are not considered legally competent, most decisions about their treatment are made by others. Instead of children making decisions about their own care, their parents or guardians make these decisions for them. The large number of people involved, legal issues related to decision-making about minors, and ethical concerns about informed consent make the treatment of children more complex (NCI, 2010e).

Supportive Care

[The material in this section is from the National Cancer Institute, 2010e.]

The parents and families of dying children need a lot of support from their healthcare team. Parents of children with cancer have reported that they find the most support from clinicians who:

- Give clear information.
- Communicate in a caring and sensitive way.
- Communicate directly with their child as needed.
- Let them know what to expect as their child nears death and help them get ready for it.

Some medical centers that specialize in cancer care for children have services that help with palliative and EOL care. These support services may include:

- Pediatric palliative care team.
- Pain service.
- Hospice care.
- Psychological and social support team.
- Bereavement program.
- Complementary and alternative medicine (CAM) services.

Other services that are helpful but may be harder to find include:

- Programs for siblings of children who are receiving EOL care.
- Hospice programs that accept children who are still receiving chemotherapy.
- Clinical trials that combine complementary and alternative treatment with standard treatment.

Even when palliative care and EOL care support services are not available, clinicians may suggest other options to parents. If parents have home healthcare support, many are able to plan and give their child EOL care at home. This can have the following positive effects:

- The child may not need to be admitted to the hospital as often.
- The parents feel that they have more control and are better able to accept their child's death.
- If the child does die in the hospital, he or she is less likely to die in an intensive care unit, which often uses invasive treatments.

There are many important ways to improve EOL care for children. When a child nears the end of life, the whole family needs compassionate medical, spiritual, emotional, and practical support. This includes the following types of help:

- Communication that is caring and sensitive to the needs of the child and the family. Communication should be based on the child's age and stage of development.
- Palliative care that includes ways to manage pain and other symptoms at the end of life. Medicines and nondrug treatments can relieve pain, agitation, itching, nausea, vomiting, and seizures. Platelet transfusions may be given to help prevent bleeding.
- Support for the emotional and spiritual needs of the child and the family that are based on differences among family members and on the family's cultural beliefs.
- Bereavement care that includes helping families to create memories with the child, such as photo albums or handprints. It also helps the family to know what to expect at the time of death and in the days, weeks, and months that follow. Bereavement support sessions may be offered after the child's death.

- Advance care planning to help the family make decisions about:
 - Types of treatment to be used.
 - Whether the family wants the child to die at home.
 - Whether the family wants hospice care.
 - Funeral arrangements.
 - Whether a DNR order will be in place.
 - Whether taking part in decisions would help the child.

- Information and advice from the healthcare team about medical, ethical, and legal issues.

Children with Cancer

[The material in this section is from the National Cancer Institute and is used with permission.]

Children are not supposed to die, and planning for a child's death is often very uncomfortable for parents, other family members, and members of the healthcare team.

Cancer is one of the leading causes of death in children in the United States, and when frontline treatment fails more than half of these children participate in clinical trials and treatments such as stem-cell transplantation. Since these strategies are sometimes effective in providing prolonged remissions, many parents choose to continue active treatment until death. Therefore, many children treated for cancer die in the hospital while receiving active treatment.

Resources to support palliative care and EOL care for children treated for cancer are often limited. One study found that only 58% of treatment centers had a pediatric palliative care team available to families, although the following related services were available:

- Pain service, 90%
- Hospice, 60%
- Psychosocial support team, 80%
- Bereavement program, 59%

Referrals to hospice care are often limited by hospice policies that do not accept patients still receiving active chemotherapy. In a survey regarding referral practices of 1,200 pediatric oncologists, hospice referrals were limited by a lack of access to inpatient hospice programs. However, pediatric oncologists indicated that, if the hospice program accepted children still receiving chemotherapy, referrals were more likely and the children were also more likely to die at home than in hospitals.

Although there is a lack of structured palliative and EOL care for children with cancer, discussions about palliation and EOL care between oncologists and parents does occur. A study of 140 parents whose children died of cancer found that if the primary oncologist discussed options and if home health support were available, 88% of parents planned how they wanted their child's EOL care to be provided, and 97% of these parents accomplished their plan. This was associated with more home deaths (72% vs. 8% who did not plan); fewer hospital admissions (54% vs. 98%); parents feeling more prepared (37% vs. 12%) and comfortable with the process (84% vs. 40%); and, for those who died in the hospital, fewer deaths in the intensive care unit (92% vs. 33%) and with intubation (21% vs. 48%).

Developmental Stages

Although each child is an individual, children go through a series of stages in their understanding of death and the events surrounding it (NIH, 2006).

- **0 to 2 years:** Although infants do not recognize death, feelings of loss and separation are part of a developing death awareness. Children who have been separated from their mothers and deprived of nurturing can exhibit changes such as listlessness, quietness, unresponsiveness to a smile or a coo, physical changes (including weight loss), a decrease in activity, and lack of sleep.
- **2 to 5 years:** Preschool children usually see death as reversible, temporary, and impersonal. Watching cartoon characters on television miraculously recover after being crushed or blown apart tends to reinforce this idea. In this age range, children often confuse death with sleep and can experience anxiety about it. In the early phases of grief, bereaved children can exhibit loss of speech and generalized distress. Children in this age group need brief and simple explanations.
- **5 to 9 years:** Between the ages of 5 and 9, most children are beginning to realize that death is final and that all living things die, but they do not see death as personal. It is not unusual for children in this age range to become curious about death, asking concrete questions about what happens to a body when it stops working. Death is personified as a separate person or spirit: a skeleton, ghost, angel of death, or bogeyman. Although death is perceived as final and frightening, it is not universal. Children in this age range begin to compromise, recognizing that death is final and real but that it mostly happens to older people (not to themselves). Grieving children can develop school phobias, learning problems, and antisocial or aggressive behaviors; can exhibit hypochondriacal concerns; or can withdraw from others.
- **9 years through adolescence:** Children of this age group begin to comprehend that death is irreversible; that all living things die and that they too will die someday. Some begin to develop philosophical views of life and death, and teenagers often become intrigued with seeking the meaning of life. Some adolescents react to their fear of death by taking unnecessary chances with their lives, trying to overcome their fears by confirming their “control” over mortality.

Children move through the developmental stages at different rates and cope with death or express their feelings in different ways, and they need sympathetic and nonjudgmental responses from adults. Careful listening and watching may provide important clues as to how to respond appropriately to a child's needs.

Each question about death deserves a simple and relevant answer. It is important to check if a child understood what was said. Also, children learn through repetition, and they may need to repeat their questions and hear them answered numerous times. It may take time for a child to understand the emotional ramifications of death.

There are also times when it is difficult to hear what children are asking. A question that may seem insensitive to an adult may be a child's request for reassurance. When a child asks a parent "When will you die?" the young child perceives death as temporary and the finality of death is not fully understood. A child may only realize that death means separation, and separation from parents with perceived loss of care is frightening.

Other problems can arise from children's misperceptions about death. Some children confuse death with sleep, particularly if they hear adults refer to death with one of the many euphemisms for sleep: "eternal rest," "rest in peace." As a result of the confusion, a child may become afraid of going to bed or taking naps.

Planning Rituals

After a death occurs, children having lost someone should be allowed to participate in and help plan the mourning rituals. As with bereaved adults, these rituals help children memorialize loved ones. Although children should never be forced to do this, they should be encouraged to participate in the aspects of funeral or memorial services with which they feel comfortable (NIH, 2006).

If the child wants to attend the funeral (or wake or memorial service), it is important that a full explanation of what to expect is given in advance. This preparation should include the layout of the room, who might be present (eg, friends and family members), what the child will see (eg, a casket and people crying), and what will happen. Surviving parents may be too involved in their own grief to give their children the attention they need; therefore, it is often helpful to identify a familiar adult friend or family member who will be assigned to care for a grieving child during a funeral (NIH, 2006).

Children and Religion

Religion can be a source of strength to many people when they are dealing with death, but if it has not played an important role in the family's life, a child may be confused or frightened by the sudden introduction of religious explanations or references. Because children tend to hear words literally, religious explanations that comfort an adult may unsettle a child. For example, the explanation, "Baby brother is with God now," or "It is God's will" could be frightening rather than reassuring to young children who may worry that God might decide to come and get them just as he did baby brother. Also, mixed messages are confusing and can deepen apprehensions and misunderstandings children may have about death. A calm statement, "He is happy now," when coupled with tears may leave children confused. Children look to adults for cues about how to behave in certain situations (NIH, 2006).

Regardless of how strong or comforting religious beliefs may be, death means the loss of a living being. Death is a time of sadness and mourning and it is important to help children accept loss and grief. Attempts to protect children may deny them the opportunity to share their feelings and receive needed support. Sharing religious beliefs can help when it is done with sensitivity to how children perceive and understand what is happening. It is important to check with them to find out how they are hearing and seeing events around them (NIH, 2006).

Cultural Considerations

The increasing population diversity in racial, ethnic, and linguistic groups who have varying cultural traits and health profiles is a challenge to the American healthcare system. The provider and the patient each bring their individual language and culture to the healthcare experience; this must be transcended to provide equal access and quality healthcare (DHHS, 2005).

Cultural Competence

Cultural and linguistic competence is a set of behaviors, attitudes, and policies that enables effective work in cross-cultural situations. **Culture** refers to patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups. **Competence** means having the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviors, and needs presented by consumers and their communities (DHHS, 2005).

Cultural competence can improve healthcare for all people. It is the way patients and clinicians can come together and talk about health concerns without cultural differences hindering the conversation. Healthcare services that are respectful of and responsive to the health beliefs, practices, and cultural and linguistic needs of patients can help bring about positive health outcomes (DHHS, 2005).

Culture and language may influence:

- Health, healing, and wellness belief systems
- How illness, disease, and their causes are perceived, both by the patient/consumer and the family
- The behaviors of patients/consumers who are seeking healthcare and their attitudes toward healthcare providers
- The delivery of services by the provider who looks at the world through one limited set of values, which can compromise access for patients from other cultures (DHHS, 2005)

It is important to understand how different cultures view healthcare and to tailor questions and treatment plans to the patient's needs. Although it is impossible to become an expert in the traditions of every culture, sensitivity to general differences can strengthen your relationship with your patients. For example, in some cultures:

- People point with the entire hand, because pointing with a finger is considered rude.
- Direct eye contact is considered disrespectful (NIA, 2008b).
- Hospice care may be seen as displacing the traditional role of the family or denying aggressive treatments for their loved ones (MarketWatch, 2007).
- The use of alternative medicines, herbal treatments, and folk remedies is common. The patient should be asked if he or she takes vitamins, herbal treatments, dietary supplements, or other alternative medicines (NIA, 2008b).
- Native healers are sometimes used (NIA, 2008b).

If the clinician is unsure about a patient's background and preferences, it is important to ask.

Interpreters

Immigrants or non-English speakers may need a medical interpreter. Almost 18% of the U.S. population speaks a language other than English at home, according to the Census Bureau. Among older people, 2.3 million report not speaking English or not speaking it very well. Federal policies require clinicians and healthcare providers who receive federal funds, such as Medicare payments, to make interpretive services available to people with limited English (NIA, 2008b).

Many clinicians rely on patients' family members or on the ad hoc services of bilingual staff members, but experts strongly discourage this practice and recommend the use of trained medical interpreters. Family members or office staff may be unable to interpret medical terminology and may inadvertently misinterpret information. They may also find it difficult to relay bad news. Although a patient may choose to have a family member translate, the patient should be offered access to a professional interpreter (NIA, 2008b).

When working with non-native English-speaking patients, it is important to ask which language they prefer to speak and whether they read and write English (and, if not, which language they prefer). Whenever possible, offer patients appropriate translations of written material or refer them to bilingual resources. If translations are not available, ask the medical interpreter to translate medical documents (NIA, 2008b).

Bereavement

Individual experiences of grief are similar across cultural boundaries, even though there are culturally distinct mourning rituals, traditions, and behavioral expressions. Healthcare professionals need to understand the part that may be played by cultural mourning practices in an individual's overall grief experience if they are to provide culturally sensitive care to their patients (NCI, 2010b).

In spite of legislation, health regulations, customs, and work rules that have greatly influenced how death is managed in the United States, bereavement practices vary in profound ways depending on one's cultural background. When assessing an individual's response to the death of a loved one, clinicians should identify and appreciate what is expected by the person's culture. Failing to carry out expected rituals can lead to an experience of unresolved loss for family members. This is often a daunting task when healthcare professionals serve patients of many ethnicities (NCI, 2010b).

Helping family members cope with the death of a loved one includes showing respect for the family's cultural heritage and encouraging them to decide how to commemorate the death. Clinicians should consider the following questions when dealing with those who are asking coping with the death of a loved one:

- What are the culturally prescribed rituals for managing the dying process, the body of the deceased, the disposal of the body, and commemoration of the death?
- What are the family's beliefs about what happens after death?
- What does the family consider an appropriate emotional expression and integration of the loss?
- What does the family consider to be the gender rules for handling the death?
- Do certain types of death carry a stigma (eg, suicide), or are certain types of death especially traumatic for that cultural group (eg, death of a child)? (NCI, 2010b)

Death, grief, and mourning are universal and natural aspects of the life process. All cultures have evolved practices that best meet their needs for dealing with death. Hindering these practices can disrupt the necessary grieving process. Understanding these practices can help clinicians to identify and develop ways to treat patients of other cultures who are grieving (NCI, 2010b).

Planning for the End of Life

When treatment choices and plans are discussed before the last days of life, it can lower the stress on both the patient and the family. End-of life planning and decision-making should begin soon after diagnosis and continue during the course of the illness. Knowing the patient's wishes can make it easier for family members to make major decisions for the patient during a very emotional time. End-of-life planning usually includes the following:

- The goals of care (eg, whether to use certain medicines during the last days of life)
- Where patients want to spend their final days
- Which treatments for EOL care the patient wishes to receive
- What type of palliative care and hospice care the patient wishes to receive (NCI, 2010g)

Advance Care Planning

The Patient Self-Determination Act guarantees patients the right to accept or refuse treatment and to complete advance medical directives. However, studies show that many patients have not participated in effective advance care planning. Despite the patient's right to accept or refuse treatment and to complete advance medical directives, research (AHRQ, 2003a) reveals that:

- Less than 50% of the severely or terminally ill patients studied had an advance directive in their medical record.
- Only 12% of patients with an advance directive had received input from their physician in its development.
- Between 65% and 76% of physicians whose patients had an advance directive were not aware that it existed.
- Having an advance directive did not increase documentation in the medical chart regarding patient preferences.
- Advance directives helped make EOL decisions in less than half of the cases where a directive existed.
- Advance directives usually were not applicable until the patient became incapacitated and "absolutely, hopelessly ill."
- Providers and patient surrogates had difficulty knowing when to stop treatment and often waited until the patient had crossed a threshold over to actively dying before the advance directive was invoked.
- Language in advance directives was usually too nonspecific and general to provide clear instruction.
- Surrogates named in the advance directive often were not present to make decisions or were too emotionally overwrought to offer guidance.

- Physicians were only about 65 percent accurate in predicting patient preferences and tended to make errors of under-treatment, even after reviewing the patient's advance directive. (AHRQ, 2003a)

The same study found that surrogates who were family members tended to make errors of overtreatment, even if they had reviewed or discussed the advance directive with the patient or assisted in its development (AHRQ, 2003a).

Advance Directives

The care of a person with a serious or potentially fatal disease usually starts after symptoms begin and a diagnosis is made and continues until the patient is in remission or cured, or until the patient has died. Ideally, EOL decisions are made early in the process, before they are needed (NCI, 2010h).

Due to the sensitive nature of these decisions, there is often a conspiracy of silence that delays or prohibits any discussion. Patients do not want to worry their families, and families are afraid that EOL discussions will cause the patient to become depressed or give up. Physicians often feel uncomfortable with these discussions and do not want to worry the patient or family. So EOL discussions are often delayed until patients are incapable of making their wishes known, and when the end nears the issues remain unresolved and decisions are made by people who may not know the patient's desires (NCI, 2010h).

Care at the end of life is sometimes inconsistent with the patients' preferences to forgo life-sustaining treatment, and patients may receive care they do not want. According to AHRQ, patient preferences to decline CPR were not translated into do-not-resuscitate orders and patients received life-sustaining treatment at the same rate regardless of their desire to limit treatment (AHRQ, 2003a).

Advance planning discussions with clinicians enable patients and families to reconcile their differences about EOL care and help the family and healthcare provider come to agreement if they need to make decisions for the patient (AHRQ, 2003a).

Research has also found that about one-third of patients would discuss advance care planning if the physician brought up the subject and about one-fourth of patients had been under the impression that advance care planning was only for people who were very ill or very old. Only 5% of patients stated that they found discussions about advance care planning too difficult (AHRQ, 2003a).

Families and surrogates who have discussed the contents of an advance directive with the patient have reported improved understanding, better confidence in their ability to predict the patient's preferences, and a stronger belief in the importance of having an advance directive (AHRQ, 2003a).

Conversations with doctors about advance care planning led to increased satisfaction among patients. Patients who talked with their families or physicians about their preferences for EOL care:

- Had less fear and anxiety
- Felt they had more ability to influence and direct their medical care

- Believed that their physicians had a better understanding of their wishes
- Indicated a greater understanding and comfort level than they had before the discussion (Clancy, 2009)

West Virginia law recognizes two types of written advance directives: the Living Will and the Medical Power of Attorney. A form is also available that combines these two into one for use in certain circumstances. There are two other related forms: the Do Not Resuscitate Form and the newer POST form:

- The **living will** allows people to tell their physicians how they want to be treated if they are terminally ill or permanently unconscious. They can specify if they do not want CPR, kidney dialysis, ventilators, or other life-prolonging treatments. They can state if they want to be simply pain-free and comfortable at the end of life. Other limitations or special requirements may be added. The living will is a formal legal document authorized by state law and must be properly witnessed and notarized (WVCEOLC, 2010).

There are many types of life-sustaining care that should be addressed when drafting a living will. These include (NCI, 2000):

- The use of life-sustaining equipment (dialysis machines, ventilators, and respirators)
- "Do not resuscitate" orders; that is, instructions not to use CPR if breathing or heartbeat stops
- Artificial hydration and nutrition (tube feeding)
- Withholding of food and fluids
- Palliative/comfort care
- Organ and tissue donation

If a decision is made not to receive "aggressive medical treatment," a patient can still receive antibiotics, nutrition, pain medication, radiation therapy, and other interventions when the goal of treatment becomes comfort rather than cure. This is called **palliative care**, and its primary focus is helping the patient remain as comfortable as possible. Patients can change their minds at any time and ask to resume more aggressive treatment. Any changes in the type of treatment a patient wants to receive should be reflected in the patient's living will.

Once a living will has been drawn up, patients should discuss their decisions with the people who matter most to them. It is advisable to make copies of the document, place the original in a safe, accessible place, and give copies to the patient's doctor, hospital, and next of kin. Patients may also want to consider keeping a card in their wallet declaring that they have a living will and where it can be found (NCI, 2010g).

- The **medical power of attorney** allows people to name a representative (and a successor representative) to make healthcare decisions for them in case they are unable to. It is also a formal legal document authorized by state law and must be properly witnessed and notarized. Once completed, copies should be given to the representative, successor representative, doctor, and local hospital, with the original kept in a safe but accessible place (usually not a safe deposit box) (WVCEOLC, 2010).

An agent may have to exercise judgment in the event of a medical decision for which the patient's wishes are not known if the patient becomes too incapacitated to make such decisions. Generally, people assign someone they know well and trust to represent their preferences (NCI, 2000).

Patients may also want to appoint someone to manage their financial affairs if they cannot. This is called a **durable power of attorney for finances**, and is a separate legal document from the medical power of attorney for healthcare. Patients may choose the same person or someone different from their healthcare proxy to act as their agent in financial matters (NCI, 2000).

- The **combined medical power of attorney/living will** can be used in situations where the person completing it specifically does not want CPR or any life-prolonging interventions used if they are terminally ill or permanently unconscious (WVCEOLC, 2010).
- A **do-not-resuscitate (DNR)** order is a document that directs what measures should or should not be taken in events such as cardiac or respiratory arrest. Physicians may recommend a DNR order when cardiopulmonary resuscitation (CPR) would be considered medically futile and ineffective in returning the person to life. Patients may also request a DNR order when CPR is not consistent with their goals of care. It is advisable for a person who has clear thoughts about these issues to speak with appointed healthcare agents (in the outpatient setting) and to have forms completed as early as possible (eg, before hospital admission). Although persons with end-stage disease and their families are often uncomfortable bringing up these issues, physicians and nurses can tactfully and respectfully address these issues appropriately and in a timely fashion (NCI, 2010g). Information and DNR cards for West Virginia can be obtained from the Center for Health Ethics and Law (see Resources).
- The **physician orders for scope of treatment (POST)** form—a standardized “hot pink” form—was created under the West Virginia Health Care Decisions Act. It contains orders of and must be signed by a physician who has personally examined the patient about their preferences for EOL care. The POST form will include directions regarding “CPR-code or no code status; level of intervention (comfort care, intermediate, or full treatment); and use or withholding of antibiotics and feeding tubes.” Use of the form is voluntary but is recommended for patients with chronic illnesses who might encounter the need for life-sustaining treatment to survive. It can be used by those with advance directives and/or DNR cards, as it is kept as the first page of a medical record or posted on the refrigerator of a patient at home and is therefore readily available in emergency situations (WVCEOLC, 2006). Additional information about the use of the POST program and West Virginia-specific materials are available on the website of the West Virginia Center for End-of-Life Care.

Having the Discussion

[The material in this section is from the Agency for Healthcare Research and Quality, 2003b.]

According to patients who are dying and their families who survive them, lack of communication with physicians and other healthcare providers causes confusion about medical treatments, conditions, and prognoses, and the choices that patients and their families need to make.

Studies have shown that discussing advance care planning and directives with their doctor increased patient satisfaction among patients age 65 years and over. Patients who talked with their families or physicians about their preferences for EOL care:

- Had less fear and anxiety
- Felt they had more ability to influence and direct their medical care
- Believed that their physicians had a better understanding of their wishes
- Indicated a greater understanding and comfort level than they had before the discussion

Patients often send cues to their health providers that they are ready to discuss EOL care by talking about wanting to die or asking about hospice. However, predicting when patients are near death is difficult. Providers can ask themselves the question: Is the patient "sick enough" today that it would not be surprising to find that the patient had died within the next year (or few months, or 6 months)? Certain situations, such as discussions about prognoses or treatment options that have poor outcomes, also lend themselves to advance care planning discussions.

AHRQ recommends a five-part process that clinicians can use to structure discussions on EOL care:

1. **Initiate a guided discussion.** During this discussion, the clinicians should share their medical knowledge of hypothetical scenarios and treatments to find out the patient's preferences in certain situations. The hypothetical scenarios should cover a range of possible prognoses and any disability that could result from treatment. By presenting various hypothetical scenarios and probable treatments and noting when the patient's preferences change from "treat" to "do not treat," the physician can begin to identify the patient's personal preferences and values.
2. **Introduce the subject of advance care planning** and offer information. Patients should be encouraged to complete both an advance directive and durable power of attorney so that treatment decisions are not left to their physicians and family members.
3. **Prepare and complete advance care planning documents.** Advance care planning documents should contain specific instructions that are effective in directing care.
4. **Review the patient's preferences on a regular basis** and update documentation. Patients should be reminded that advance directives can be revised at any time.
5. **Apply the patient's desires to actual circumstances.** Even if patients require a decision for a situation that was not anticipated and addressed in their advance directive, clinicians and surrogates still can make an educated determination based on the knowledge they have about the patients' values, goals, and thresholds for treatment.

Chronic Illness and EOL Planning

[The material in this section is from the Agency for Healthcare Research and Quality, 2003b.]

Advance care planning should not be just for those people who are terminally ill or facing imminent death, but also for patients suffering from chronic illness. Because healthcare providers are often in the best position to know when to bring up the subject of EOL care, they must be able to initiate and guide advance-care planning discussions.

The majority of people who die in the United States (80%–85%) are Medicare beneficiaries age 65 and over. Most of those people die from chronic conditions such as heart disease, cerebrovascular disease, chronic obstructive pulmonary disease (COPD), diabetes, Alzheimer's disease, and renal failure. Approximately twenty-two percent of deaths in people age 65 and over are from cancer.

People with terminal cancer generally follow an expected course, or "trajectory," of dying. Many maintain their activities of daily living until about 2 months prior to death, after which most functional disability occurs.

In contrast, people with chronic diseases such as heart disease or COPD often go through periods of slowly declining health marked by sudden severe episodes of illness requiring hospitalization, from which the patient may recover. This pattern can repeat itself many times, with the patient's overall health steadily declining, until the patient dies. For these individuals there is considerable uncertainty about when death will occur.

Patients who suffer from chronic conditions such as stroke, dementia, or the frailty of old age go through a third trajectory of dying, with a steady decline in mental and physical ability that finally results in death. It is much more difficult to estimate how long these patients will live than for those who are dying of cancer and they are often not told that their disease is terminal.

When patients are hospitalized for health crises resulting from their chronic incurable disease, medical treatment cannot cure the underlying illness but may resolve the immediate emergency and possibly extend the patient's life. During any one of these crises the patient may be close to death, yet there often is no clearly recognizable threshold between being very ill and actually dying. As illness progresses, patients may become too incapacitated to speak for themselves and treatment decisions are usually made jointly between the patient's physician and family or surrogate. However, unless advance planning has been done, patient preferences are often not known.

Ideally, the patient, the family, and the physician have had discussions about treatment options, including the length and invasiveness of treatment, chance of success, overall prognosis, and the patient's quality of life during and after the treatment. These discussions should continue as the patient's condition changes. Frequently, however, such discussions are not held. If the patient becomes incapacitated due to illness, the patient's family and physician must make decisions based on what they think the patient would want.

Transitional Care Planning

A **transition** is a passage from one phase to another. Transitional care planning helps a patient's care continue without interruption through different phases of an illness. For example, as a cancer patient's treatment goals change or the place of care changes the patient may encounter problems with the transition (NCI, 2010j).

With diseases such as cancer, nearly 90% of care is delivered in outpatient settings. This means increased responsibility for the patient and family and requires a coordinated approach by the healthcare system. There must be careful planning among the various inpatient and outpatient settings to ensure continuity and optimal care. For successful treatment, it is essential to have a coordinated healthcare team, ongoing support and education, and an involved patient and family (NCI, 2010g).

Quality of care is at risk during transitions if the planning and delivery of home care services to patients and their families are not coordinated. The demands of illness also place families at risk for job loss and economic hardship as they struggle to care for their family members at home. The most vulnerable of those experiencing cancer—such as those with a low income, urban-dwelling minorities, and those in a rural setting—may be at a higher risk of experiencing fragmented care (NCI, 2010g).

Patients will need to make decisions that balance disease status and treatment options with family needs, finances, employment, spiritual or religious beliefs, and quality of life. There may be practical problems such as finding an appropriate rehabilitation center, obtaining special equipment, or paying for needed care. There may be mental health problems such as depression or anxiety. Transitional planning helps identify and manage these problems and reduce stress so the transition can go smoothly without interruption of care (NCI, 2010f)

Transitional care planning may include support and education for the patient and family and referral to resources. Ideally, it involves a team approach by the patient's healthcare providers. It is important that there be close communication between members of the team and that this communication include the patient and family (NCI, 2010f).

Goals of care for cancer, for example, may change as the disease changes. Each type of cancer requires different care, and the goals of patients' treatment may change as their disease gets better or worse. The care may include any of the following:

- **Active treatment:** Treatment given to cure the disease.
- **Supportive care:** Care given to prevent or treat as early as possible the symptoms of the disease; side effects caused by treatment of the disease; and psychological, social, and spiritual problems related to the disease or its treatment.
- **Palliative therapy:** Treatment given to relieve symptoms and improve the patient's quality of life. Palliative therapy may be given along with other treatments, or when treatment is no longer curative, to make the patient comfortable at the end of life.
- **Transitional care:** Planning that can help the patient and family with medical, practical, and emotional issues that arise as they adjust to different levels and goals of care (NCI, 2010f)

A patient may receive care in several different settings during the course of the illness, but most of the care received by people with cancer is provided in places other than a hospital. Patients may transition from hospital or outpatient care, to care at home, a nursing home, rehabilitation center, or to a hospice team for EOL care.

When a patient moves from one place of care to another, the process of planning for the move is called **discharge planning**. This may involve a case manager who acts on the patient's behalf when dealing with the hospital, visiting nurses, healthcare companies, rehabilitation facilities, nursing homes, and other groups that provide the care needed. The case manager is a link to resources and services in the community and can arrange for the provision of services, including patient and family education and referrals (NCI, 2010f).

Different types of care are available for different needs. Transitional care may include management of the patient's medical condition and rehabilitation, plus supportive services to ensure basic needs such as comfort, hygiene, safety, and nutrition. It may also include supportive services for educational, social, spiritual, and financial needs.

Healthcare specialists and other caregivers work as a team, providing services to patients in their homes, clinics, and other settings. The team may include:

- Doctors
- Nurses
- Dietitians
- Physical therapists
- Occupational therapists
- Social workers
- Mental health professionals
- Clergy or other religious leaders
- Companions
- Home care aides (NCI, 2010f)

Programs that provide care may include:

- Bereavement programs
- Community support groups
- Employment counseling agencies
- Home health agencies
- Home infusion agencies
- Hospice programs
- Legal aid organizations
- Palliative care programs
- Medication support (NCI, 2010f)

Reassessment of the patient should be done at crisis points throughout the course of the illness. These crisis or transition points can occur at times of disease progression or relapse or at times of functional change. The shift into the post-treatment period also represents a significant transition.

There may be other critical times for the patient, such as the death or illness of a loved one, job loss, transition to a nursing home, or a change in personal mobility. Changes in the patient's status can occur rapidly, and reassessment should be built into any outpatient or home care routine (NCI, 2010g).

Healthcare providers must recognize that any serious illness comes with losses and, as a result, bereavement. Cancer and other serious diseases temporarily or permanently disrupt lives, dreams, hopes, careers, aspirations, integrity, and a sense of security. If the emotional crisis generated by an illness is successfully managed, patients and families can experience psychological growth and maturity. Psychosocial management of a serious illness, regardless of its outcome, should be an integral part of care (NCI, 2010g).

Home Care Considerations

Families and other informal caregivers are essential in meeting a patient's physical and psychosocial needs and in accomplishing treatment goals. Caregivers provide substantial amounts of assistance with daily living tasks. They watch over symptoms and general health, monitor and administer medications, and coordinate care among health and social service providers, as well as providing emotional support. This is particularly true when patients live with a prolonged illness such as dementia, which has a median life expectancy of 3.5 years (NLM, 2004a).

Caring for a patient at home is often a difficult time for families. There are increased demands placed on the time, energy, and emotions of those who care for a chronically ill or dying person. Many families have numerous out-of-home responsibilities and, in addition, some family members might be physically or psychosocially compromised and thus unable to assume the primary care role.

The following factors need to be assessed when determining whether a spouse or caregiver can handle home care:

- The caregiver's age, health, motivation, and sex (women are more likely to provide home care)
- The length of hospital stay (prolonged stay may complicate transition to home care)
- Other demands on the caregiver
- The degree of patient distress (particularly pain)
- The technical nature of care
- Decision-making skills required for care delivery
- Access to available healthcare which may be limited for the poor and for those who live in rural settings (NCI, 2010i)

The family's motivation and ability to provide care for the patient must be assessed. The assessment must include any pre-existing interpersonal conflicts and the family's beliefs and values with regard to home care, dying, and the use of opioids for pain control. Adequate pain and symptom management is a key component to successful home management, but this can only be accomplished if the family and primary caregiver understand the need for the control of pain and other symptoms. Healthcare providers and caregivers need to understand that uncontrolled symptoms, particularly poorly controlled pain, can dramatically increase the physical and psychological burdens of caregiving.

Caregiver responsibilities do not end with admission to a nursing home, where they continue to provide significant personal support. Families and other caregivers face emotional, physical, and economic consequences and may lack reliable support for their responsibilities. A recent study surveyed nearly a thousand caregivers and found that 35% reported substantial care needs that consumed time and money and affected employment. Financial and nonfinancial caregiving burdens were related to depression as well as to thoughts about physician-assisted suicide and euthanasia. Almost half of personal bankruptcy is associated with medical illness, and adverse financial circumstances may affect family decision-making (AHRQ, 2004a).

Home caregivers should know who to call for support or advice when problems arise. As an illness progresses it is important to have consistent personnel who know the patient's situation.

Emotional Support

[This section is taken from National Cancer Institute, 2001.]

Even though everyone has different needs, some emotions are common to most dying patients. These include fear of abandonment and fear of being a burden. They also have concerns about loss of dignity and loss of control. Caregivers can provide comfort in the following ways:

- Keep the person company—talk, watch movies, read, or just be with the person.
- Allow the person to express fears and concerns about dying, such as leaving family and friends behind. Be prepared to listen.
- Be willing to reminisce about the person's life.
- Avoid withholding difficult information. Most patients prefer to be included in discussions about issues that concern them.
- Reassure the patient that you will honor advance directives, such as living wills.
- Ask if there is anything you can do.
- Respect the person's need for privacy.

Insurance and Financial Considerations

[This section is taken from National Cancer Institute, 2010.]

Other important issues in transitional care planning include insurance coverage, the availability of community resources, and legal concerns such as living wills and healthcare proxies. As discussed earlier, advance directives and the need for durable power of attorney should be discussed with the patient and the family. It is important that patients make their wishes known to the physician and the family, well in advance if possible. Healthcare personnel need to be cognizant of widely varying cultural approaches to these discussions.

Most insurance companies cover home care, but some policies limit services to specified settings; for example, payment may depend on the patient having already been hospitalized or needing skilled nursing services. It is important to know insurance limits on specific services as well as lifetime limitations.

A primary care physician, nurse, or social worker may need to assume the role of patient advocate when dealing with third-party insurers, case managers, and managed care companies. For these reasons it is important to design a home care plan that provides adequate safety to the patient, is least distressing to the family, and utilizes resources appropriately. It is often helpful to explore other resources that do not require insurance or patient payment, including sectarian or nonsectarian family agencies that may provide limited unskilled services. Nursing assistants and aides (unskilled nursing services) are usually not covered by insurance; however, hospice care may cover this expense. Private home care services provide this care, but at the expense of the patient and family.

Common Signs and Symptoms

When a person is nearing the end of life, effective prevention and relief of symptoms becomes a high priority. Symptoms are subjective indicators of distress and the primary reason patients seek care, and they remain important even when the underlying causes of illness are increasingly difficult to modify (NCI, 2010c).

Comfort care is an essential part of medical care at the end of life. The goal is to prevent or relieve suffering as much as possible while respecting the dying person's wishes. Common symptoms at the end of life include depression, pain, fatigue, coughing, shortness of breath, rattle, nausea and vomiting, delirium, and fever. Bleeding may also occur (NCI, 2010c).

Depression in Adults

[This section is taken largely from the National Cancer Institute, 2010a.]

Sadness and grief are normal reactions to the crises faced during cancer and other terminal illnesses, and will be experienced at times by all people. Preparatory grief is the normal reaction of a terminally ill patient who is preparing for separation from this world.

Because sadness and grief are common, it is important to distinguish between normal levels of sadness and depression. An important part of care for the dying patient is the recognition of depression that needs to be treated. Some people may have more trouble adjusting to a terminal diagnosis than others.

Major depression is not simply sadness or a blue mood. Major depression affects about 25% of cancer patients and has common symptoms that can be diagnosed and treated. The symptoms of major depression include the following:

- Having a depressed mood for most of the day and on most days
- Loss of pleasure and interest in most activities
- Changes in eating and sleeping habits
- Nervousness or sluggishness
- Tiredness
- Feelings of worthlessness or inappropriate guilt
- Poor concentration
- Constant thoughts of death or suicide

Major depression may be treated with a combination of counseling and medications such as antidepressants. A primary care physician may prescribe medications for depression and refer the patient to a psychiatrist or psychologist.

Antidepressants are usually effective in the treatment of depression and its symptoms. Unfortunately, antidepressants are not often prescribed for cancer patients; about 25% of all cancer patients are depressed, but only about 16% receive medication for the depression.

The choice of antidepressant depends on the patient's symptoms, potential side effects of the antidepressant, and the person's individual medical problems and previous response to antidepressant drugs.

Depression in Children

[This section is taken largely from the National Cancer Institute, 2010a.]

Most children cope with the emotions related to cancer; however, a small number of children develop psychological problems—including depression, anxiety, sleeping problems, and relationship problems—and are uncooperative about treatment. A mental health specialist should treat these children.

Children with severe late effects of cancer have more symptoms of depression. Anxiety usually occurs in younger patients, while depression is more common in older children.

The term **depression** refers to a symptom or a set of symptoms or conditions that occur together to suggest a disorder. A diagnosis of depression depends on how severe the symptoms are and how long they last. Depression is marked by a response that lasts a long time and is associated with sleeplessness, irritability, changes in eating habits, and problems at school and with friends. Depression should be considered whenever any behavioral problem continues. Depression does not refer to temporary moments of sadness, but rather to a disorder that affects development and interferes with the child's progress.

Some signs of depression in the school-aged child include the following:

- Not eating
- Inactivity
- Looking sad
- Aggressive behavior
- Crying
- Hyperactivity
- Physical complaints
- Fear of death
- Frustration
- Feelings of sadness or hopelessness
- Self-criticism
- Frequent daydreaming

- Low self-esteem
- Refusing to go to school
- Learning problems
- Slow movements
- Showing anger towards parents and teachers
- Loss of interest in activities that were previously enjoyed

Some of these signs can occur in response to normal developmental stages; therefore, it is important to determine whether they are related to depression or a developmental stage. Determining a diagnosis of depression includes evaluating the child's family situation, as well as the child's level of emotional maturity and ability to cope with illness and treatment; the child's age and state of development; and the child's self-esteem and prior experience with illness.

A comprehensive assessment for childhood depression is necessary for effective diagnosis and treatment. Evaluation of the child and family situation focuses on the child's health history; observations of the child's behavior by parents, teachers, or healthcare workers; interviews with the child; and use of psychological tests.

Childhood depression and adult depression differ because of the developmental issues of childhood. To diagnose depression in children, look for a sad mood (a sad facial expression in children younger than 6) with at least four of the following signs or symptoms present every day for a period of at least 2 weeks:

- Appetite changes
- Either not sleeping or sleeping too much
- Being either too active or not active enough
- Loss of interest or pleasure in usual activities
- Signs of not caring about anything (in children younger than 6)
- Tiredness or loss of energy
- Feelings of worthlessness
- Self-criticism or inappropriate guilt
- Inability to think or concentrate well
- Constant thoughts of death or suicide

Individual and group counseling are usually used as the first treatment for a child with depression; they are directed at helping the child to master difficulties and develop in the best way possible. Play therapy may be used as a way to explore younger children's view of themselves, the disease, and the treatment. A physician may prescribe medications (eg, antidepressants) for children.

Pain

Effective pain management is a palliative focus for many conditions, and pain is among the most debilitating and feared symptoms that patients and families face. Studies demonstrate that 70% to 100% of cancer patients experience pain (AHRQ, 2004a).

In the last days of life, a patient may not be able to swallow pain medicine. When patients cannot take medicines by mouth, it may be given by placing it under the tongue or into the rectum, by injection or infusion, or by placing a patch on the skin. These methods can be used at home with a doctor's order (NCI, 2010d).

Pain during the final hours of life can usually be controlled. Opioid analgesics work very well to relieve pain and are commonly used at the end of life. Some patients worry that the use of opioids may cause death to occur sooner, but studies have shown no link between opioid use and early death (NCI, 2010d).

In order to treat pain, it must be measured. The patient and the doctor should measure pain levels at regular intervals, at each new report of pain, and after starting any type of treatment for pain. The cause of the pain must be identified and treated promptly (NCI, 2010d).

To help the care providers determine the type and extent of the pain, patients can describe the location and intensity of their pain, any aggravating or relieving factors, and their goals for pain control. The family/caregiver may be asked to report for a patient who has a communication problem involving speech, language, or a thinking impairment. The healthcare provider should help the patient describe the following:

- **Pain:** The patient describes the pain, when it started, how long it lasts, and whether it is worse during certain times of the day or night.
- **Location:** The patient shows exactly where the pain is on the body, or on a drawing of a body, and where the pain goes if it travels.
- **Pattern:** The patient reports whether there have been changes in where the pain is, when the pain occurs, and how long it lasts, or if there is new pain.
- **Intensity or severity:** The patient keeps a diary of the degree or severity of pain.
- **Aggravating and relieving factors:** The patient identifies factors that increase or decrease the pain. The patient also identifies symptoms that are most troublesome, since they are not always the most serious or severe.
- **Personal response to pain:** Feelings of fear, confusion, or hopelessness about the disease, its prognosis, and the causes of pain can affect how a patient responds to and describes the pain. For example, a patient who thinks pain is caused by spreading cancer may report more severe pain or more disability from the pain.
- **Behavioral response to pain:** The healthcare provider and/or caregivers note behaviors that may suggest pain in patients who have communication problems.
- **Goals for pain control:** With the healthcare provider, patients decide how much pain they can tolerate and how much improvement they may achieve. The patient uses a daily pain diary to increase awareness of pain, gain a sense of control of the pain, and receive guidance from healthcare providers on ways to manage the pain (NCI, 2010d).

Pain Intensity Scales

[This section is taken largely from the National Institutes of Health, 2007.]

Pain scales are used to measure how intensely individuals are feeling pain and to monitor the effectiveness of treatments. Some of the scales are appropriate for children and adults and others are used for infants. A balance must be maintained between the effective dose of a pain medication and the production of toxic side effects.

The Numeric Rating Scale is used for adults and children more than 9 years old in all patient care settings who are able to use numbers to rate the intensity of their pain. The patient is asked any one of the following questions:

- What number would you give your pain right now?
- What number on a 0 to 10 scale would you give your pain when it is the worst that it gets and when it is the best that it gets?
- At what number is the pain at an acceptable level for you?

When these explanations are not sufficient for the patient, it is sometimes helpful to further explain the Numeric Rating Scale in the following manner:

- 0 = No pain
- 1 to 3 = Mild pain (nagging, annoying, interfering little with ADLs)
- 4 to 6 = Moderate pain (interferes significantly with ADLs)
- 7 to 10 = Severe pain (disabling; unable to perform ADLs)

The Wong-Baker Faces Pain Rating Scale can be used for adults and children over 3 years old in all patient care settings. The patient is asked to point to the picture that best describes the pain he or she is experiencing.

The COMFORT Scale can be used for infants, children, and adults in a critical care or operative setting who are unable to use the Numeric Rating Scale or the Wong-Baker Faces Pain Rating Scale.

There are nine categories that are scored from 1 to 5, resulting in a total score between 9 and 45.

- Alertness
- Calmness
- Respiratory distress
- Crying
- Physical movement
- Muscle tone
- Facial tension
- Blood pressure baseline
- Heart rate baseline

The CRIES Pain Scale is used for neonates (0 to 6 months). There are five categories that are scored from 0 to 2, resulting in a total score between 0 and 10.

The FLACC Scale can be used for infants and children from 2 months to 7 years who are unable to validate the presence or to quantify the severity of pain. Each of the following categories is scored from 0 to 2, which results in a total score between 0 and 10:

- (F) Faces
- (L) Legs
- Activity
- Cry
- Consolability

The Checklist of Non-verbal Indicators can be used for adults who are unable to validate the presence or to quantify the severity of pain using either the Numerical Rating Scale or the Wong-Baker Faces Pain Rating Scale. Having used one or more of the scales, the interdisciplinary team, in collaboration with the patient and family, can then determine appropriate interventions in response to the pain ratings.

World Health Organization Guidelines

The World Health Organization (WHO) has developed a three-step **pain relief ladder** outlining what pain medications should be used and how they should be taken for cancer pain relief. This ladder has proven to be effective when used for other causes of pain as well (WHO, n.d.). The three steps are:

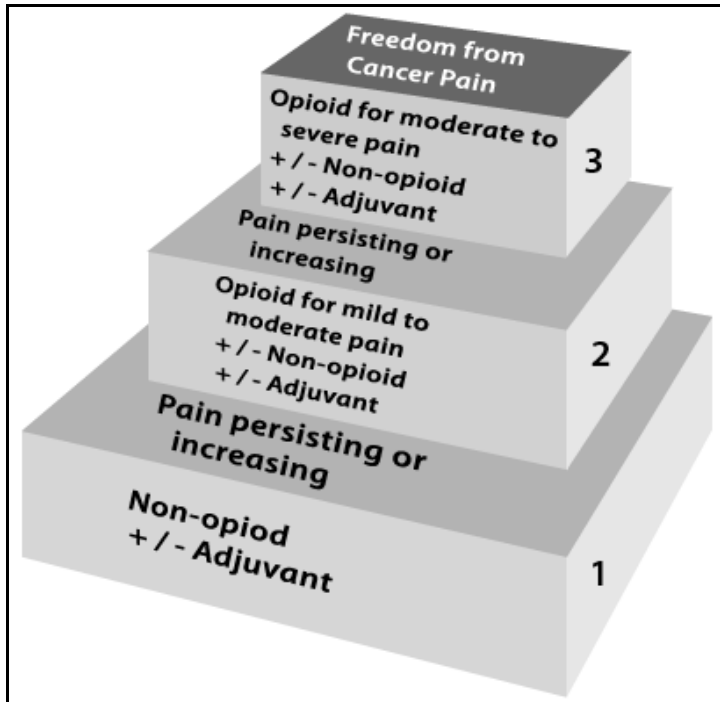
1. If pain occurs, there should be prompt oral administration of drugs in the following order: nonopioids such as aspirin and acetaminophen;
2. Then, as necessary, mild opioids (codeine); then strong opioids such as morphine should be used, until the patient is free of pain.
3. To calm fears and anxiety, additional drugs—adjuvants—should be used.

Adjuvant drugs are medications usually used for conditions other than pain. These medications are used to enhance analgesia and to reduce side effects of other pain relievers (eMed Expert, 2009).

To maintain freedom from pain, drugs should be given by the clock, that is, every 3 to 6 hours, rather than on demand. This three-step approach of administering the right drug in the right dose at the right time is inexpensive and 80% to 90% effective. Surgical intervention on appropriate nerves may provide further pain relief if drugs are not wholly effective.

A pain scale that is appropriate for a patient's age and mental status is used to quantify the pain in order to keep the pain level less than four. There must always be balance between increasing doses of pain medication and adverse side effects such as excessive sedation, nausea, vomiting, confusion, and rashes (Robbins, Rosenbaum and Shapiro, 2008).

WHO's Pain Relief Ladder



This image is used courtesy of the World Health Organization.

West Virginia Pain Management Guidelines

In 1998 the West Virginia Legislature enacted the Management of Intractable Pain Act to protect physicians from sanctions or disciplinary action due to prescribing pain-relieving drugs for intractable pain provided they were doing so within their scope of practice. The law was amended in 2002 to include policy or position statements as “accepted guidelines” and to protect physicians who were following such a guideline. In 2009 the legislature enacted the Management of Pain Act (H.B. 2839), which amended and re-enacted certain portions of the state code dealing with definitions, including those of pain and accepted guidelines, and addressed the protection of physicians from prosecution when following the law. The definition of pain removed the term “intractable” (WVCEOLC, 2009; 2011).

Pain management and the prescribing of opioids remains a challenge for physicians in West Virginia, which has an enormous problem with prescription drug abuse. Data analysis recently demonstrated that in the decade ending in 2009, West Virginia’s per capita consumption of most opioids rose 200% to 400%. Good pain evaluation takes time, those who are addicted can be clever, and the magnitude of the problem has caused some physicians to simply cease prescribing opioids. The director of the West Virginia Center for End-of-Life Care acknowledges the complexity of the problem and the need for balance (Knezevich, 2011).

Myoclonic Jerks

[The material in this section is from National Cancer Institute, 2010c, 2010d.]

Myoclonic jerks are sudden uncontrollable muscle twitches or jerks that may be a side effect of taking high doses of opioids for long periods of time (although there may be other causes, as well). Myoclonic jerks can occur in the arms or legs or may be experienced as hiccups. In patients taking opioids, it may begin with jerking movements that happen occasionally but gradually increase over time. Rarely, there is constant jerking of muscle groups all over the body.

When opioids are the cause of myoclonic jerking, changing to another opioid may help. Patients respond to these medications in different ways and, in some people, certain opioids may be more likely than others to cause this symptom. When the patient is very near death, medicine to stop the myoclonic jerking may be given instead of changing the opioid. When jerking is severe, drugs may be used to calm the patient down, relieve anxiety, and help the patient sleep.

The results of pain management should be measured by monitoring for a decrease in the severity of pain and improvement in thinking ability, emotional well-being, and social functioning. The results of taking pain medication should also be monitored. Developing a higher tolerance for a drug and becoming physically dependent on the drug for pain relief does not mean that the patient is addicted. Patients who have a history of drug abuse may need and tolerate higher doses of medication to control pain.

Fatigue

Fatigue can have many causes at the end of life. These include physical and mental changes and side effects of treatments. Drugs that increase brain activity, alertness, attention, and energy may be helpful (NCI, 2010c).

Shortness of Breath

[The material in this section is from National Cancer Institute, 2010c.]

Feeling short of breath is common during the final days or weeks of life and is often caused by advanced cancer. Other causes include the following:

- Build-up of fluid in the abdomen
- Loss of muscle strength
- Hypoxemia
- Chronic obstructive pulmonary disease (COPD)
- Pneumonia
- Infection

The use of opioids and other methods can help the patient breathe more easily. Very low doses of an opioid may relieve shortness of breath in patients who are not taking opioids for pain. Higher doses may be needed in patients who are taking opioids for pain or who have severe shortness of breath.

Other ways to help patients who feel short of breath include:

- Treating anxiety caused by shortness of breath
- Directing a cool fan towards the patient's face
- Having the patient sit up
- Having the patient do breathing and relaxation exercises, if able
- Using acupuncture or acupressure
- Giving antibiotics if shortness of breath is caused by an infection
- Giving extra oxygen if shortness of breath is caused by hypoxemia

In rare cases, shortness of breath may not be relieved by any of these treatments and sedation with drugs may be needed to help the patient feel more comfortable.

Some patients have spasms of the air passages in the lungs along with shortness of breath. Bronchodilators or steroid drugs (which relieve swelling and inflammation) may relieve these spasms.

Cough

Chronic coughing at the end of life may add to a patient's discomfort. Repeated coughing can cause pain and loss of sleep, increase tiredness, and worsen shortness of breath. At the end of life, the decision may be to treat the symptoms of the cough rather than finding and treating the cause. The following types of drugs may be used to make the patient as comfortable as possible:

- Opioids to stop the coughing
- Corticosteroids to shrink swollen lymph vessels
- Antibiotics to treat infection
- Bronchodilators to decrease wheezing and coughing from COPD
- Diuretics to relieve coughing caused by congestive heart failure (NCI, 2010c)

Finally, some medications (eg, ACE inhibitors for high blood pressure or heart failure) can cause cough.

Death Rattle

[This section is taken largely from National Cancer Institute, 2010c.]

Rattle occurs when fluids build up in the throat and airways in a patient who is too weak to clear the throat. Death rattle can be caused by saliva pooling at the back of the throat or by fluid in the airways from an infection, tumor, or excess fluid in body tissues. Drugs may be given to decrease the amount of saliva in the mouth or to dry the upper airway. Since most patients with rattle are unable to swallow, these drugs are usually given in patches on the skin or by infusion.

Raising the head of the bed, propping the patient up with pillows, or turning the patient to either side may help relieve rattle. If the rattle is caused by fluid at the back of the throat, excess fluid may be gently removed from the mouth using a suction tube. Fluid in the airways is not removed by suction, because the action would cause severe physical and mental stress to the patient.

At the end of life, the body needs less food and fluid. Reducing food and fluids can lessen the excess fluid in the body and greatly relieve rattle. Death rattle is a sign that death may occur in hours or days and can be very upsetting for those at the bedside, but it does not seem to be painful for the patient.

Nausea and Vomiting

Nausea, vomiting, constipation, and loss of appetite are common EOL complaints. Causes and treatments vary but there are medications to control nausea and vomiting or relieve constipation. Often, oral administration of medication is not possible and alternative routes (eg, rectal suppositories, patches) must be considered. Patients who want to eat, but are too tired or weak, can be assisted with feeding. If loss of appetite is a problem, you can encourage the patient to eat favorite foods in frequent, small meals rather than three larger ones (NIA, 2010).

The patient should not be forced to eat. Going without food and/or water is generally not painful, and eating can add to discomfort. Losing one's appetite is a common and normal part of dying. A conscious decision to give up food can be part of a person's acceptance that death is near (NIA, 2010).

Delirium

[This section is taken from National Cancer Institute, 2010c.]

Delirium is common during the final days of life. Some patients may be confused, nervous, restless, and have hallucinations while others may be quiet and withdrawn. Delirium can be caused by the direct effects of cancer, such as a growing tumor in the brain. Other causes include the following:

- A higher- or lower-than-normal amount of certain chemicals in the blood that support the function of the heart, kidneys, nerves, and muscles
- Side effects of drugs or drug interactions (changes in the way a drug acts in the body when taken with certain other drugs, herbal medicine, or foods)
- Stopping the use of certain drugs or alcohol
- Dehydration (the loss of needed water from the body)
- A full bladder or constipation
- Shortness of breath

Delirium may be controlled by finding and treating the cause. Depending on the cause, treatment may include the following:

- Giving drugs to fix the level of certain chemicals in the blood
- Stopping or lowering the dose of the drugs that are causing delirium
- Stopping drugs (eg, drugs to lower cholesterol) that may cause drug interactions but are no longer useful at the end of life
- Treating dehydration with intravenous fluids

For some patients in the last hours of life, the decision may be to treat only the symptoms of delirium and make the patient as comfortable as possible.

Hallucinations that are not related to delirium often occur at the end of life. It is common for dying patients to have hallucinations that include loved ones who have already died and it is normal for family members to feel distress when these hallucinations occur. Speaking with clergy, the hospital chaplain, or other religious advisors is often helpful.

Fever

Fever and infections are common at the end of life. Because patients often have many medical problems during this time, it can be hard to determine the cause of a fever and whether treatment will help the patient. Patients near the end of life may choose not to treat the cause of the fever but only to receive comfort measures (NCI, 2010c).

Hemorrhage

[This section is taken from National Cancer Institute, 2010c.]

Hemorrhage is rare but may occur in the last hours or minutes of life in patients who have certain cancers or disorders. Blood vessels may be damaged by certain cancers or cancer treatments such as radiation. Tumors can also damage blood vessels. Patients with the following conditions are at risk for hemorrhage:

- Head and neck cancers
- Stomach cancer
- Esophageal cancer
- Leukemias and other blood cancers
- Blood clotting disorders

Making the patient comfortable is the main goal of care at the end of life. Sudden bleeding in a dying patient signals that they end of life is near and resuscitation usually will not work. The main goal of care is to help the patient be calm and comfortable and to support family members.

The following steps can be taken when bleeding occurs in the last hours of life:

- Cover the area with dark-colored towels so the blood is not seen
- Change towels and keep the area clean
- Speak calmly to the patient and to family members
- Let the patient know if loved ones are there

Fast-acting drugs may help calm the patient during this time.

Palliative Sedation

The decision whether to sedate a patient at the end of life is difficult and involves many factors. The goal of palliative sedation is not to shorten life but to make the end of life more comfortable. Palliative sedation may be considered to relieve uncontrolled physical suffering, depression, or anxiety. Certain drugs are given to sedate the patient and may be combined with treatment for pain and agitation. Palliative sedation may be temporary, as in patients with delirium or trouble breathing (NCI, 2010a).

Patients' thoughts and feelings about EOL sedation may depend greatly on their own culture and beliefs. Some patients who are nearing the end of life may want to be sedated. Other patients may wish to have no procedures, including sedation, just before death. It is important for patients to tell family members and healthcare providers of their wishes about sedation at the end of life. When patients make their wishes about sedation known ahead of time, doctors and family members can be sure they are doing what the patient would want (NCI, 2010a).

Spiritual Issues

[This section is taken from National Institute on Aging, 2010).]

People nearing the end of life may have spiritual needs as compelling as their physical concerns. Spiritual needs can involve finding meaning in one's life and ending disagreements with others. The dying person might find peace by resolving unsettled issues with friends or family. Visits from a social worker or a counselor may also help. Religious faith is very important to many people. Praying, talking with someone from their religious community, reading a religious text, or listening to religious music may bring comfort.

Family and friends can talk to the dying person about the importance of their relationship. Adult children can share the ways their loved one has influenced the course of their lives. Grandchildren can let their grandparents know how much they have meant to them and friends can relate how they value years of support and companionship. Family and friends who can't be present could send a recording of what they would like to say or a letter to be read out loud.

Sharing memories of good times is another way some people find peace near death. This can be comforting for everyone. Some physicians think it is possible that unconscious patients might still be able to hear what is going on around them, so family members should be counseled to talk to, not about, the person who is dying. When entering the room, people should always identify themselves to the patient, and friends and family should be encouraged to talk to the dying person about fond memories.

There may be times when a dying person who has been confused suddenly seems coherent. Families should take advantage of these moments, but understand that they might be only temporary, and not necessarily a sign their loved one is getting better.

The Final Days and Hours

[This section is taken from National Cancer Institute, 2010c.]

Most people are not familiar with the signs that death is near. The healthcare team should provide family members with information about the changes they may see in the final hours and how to help their loved one during this time. Knowing what to expect can prepare families for the death of their loved one and make this time less stressful and confusing.

As the end of life approaches, patients often lose the desire to eat or drink, and may refuse food and fluids. The family may give ice chips or swab the mouth and lips to keep them moist. Forcing food and fluids can make the patient uncomfortable or cause choking. Family members may find other ways to show their love for the patient, such as massage.

Patients may withdraw and spend more time sleeping. They may answer questions slowly or not at all, seem confused, and show little interest in their surroundings. Most patients are still able to hear after they are no longer able to speak. It may give some comfort if family members continue to touch and talk to the patient, even if the patient does not respond.

Some of the following physical changes may occur in the patient at the end of life:

- The patient may feel tired or weak.
- The patient may pass less urine and it may be dark in color.
- The patient's hands and feet may become blotchy, cold, or blue. Caregivers can use blankets to keep the patient warm. Electric blankets or heating pads should not be used.
- The heart rate may go up or down and become irregular.
- Blood pressure usually goes down.
- Breathing may become irregular, with very shallow breathing, short periods of not breathing, or deep, rapid breathing.

Ventilator Use During the Last Days of Life

[This section is taken from National Cancer Institute, 2010c.]

Ventilator use may keep the patient alive after normal breathing stops, or during the last days of life a ventilator may be used to assist breathing. If the goal of care is to help the patient live longer, a ventilator may be used according to the patient's wishes. If ventilator support stops helping the patient or is no longer what the patient wants, the patient, family, and healthcare team may decide to discontinue it.

Before the ventilator is turned off, family members must be given information about what to expect. They need to be told how the patient may respond and about pain relief or sedation to keep the patient comfortable. Family members should be given time to contact other loved ones who may wish to be present. Chaplains or social workers may be called to help and support the family.

When a Loved One Dies at Home

[This section is taken from National Cancer Institute, 2002.]

After the patient dies, family members and caregivers may wish to stay with the patient for a while. There may be certain customs or rituals that are important to the patient and family at this time. These might include rituals for coping with death, handling the patient's body, making final arrangements for the body, and honoring the death. The healthcare team should ask about any customs or rituals family members want performed after the patient's death.

When the family is ready, healthcare providers, hospice staff, social workers, or spiritual leaders can explain the following steps that need to be taken once death has occurred:

- Place the body on its back with one pillow under the head. If necessary, caregivers or family members may wish to put the patient's dentures or other artificial parts in place.
- If the patient is in a hospice program, follow the guidelines provided by the program. A caregiver or family member can request a hospice nurse to verify the patient's death.

- Contact the appropriate authorities in accordance with local regulations. If the patient has requested not to be resuscitated through a Do-Not-Resuscitate (DNR) order or other mechanism, do not call 911.
- Contact the patient's doctor and funeral home.
- When the patient's family is ready, call other family members, friends, and clergy.
- Provide or obtain emotional support for family members and friends to cope with their loss.

Grief, Bereavement, and Mourning

[This section is taken from National Cancer Institute, 2010b.]

People cope with the loss of loved ones in different ways. The manner in which people grieve depends on their personality and the relationship with the person who has died. The way people cope with grief is affected by the way the disease progressed, the cultural and religious background, coping skills, mental history, support systems, and the social and financial status. Grief, bereavement, and mourning are often used interchangeably, however they have different meanings.

Grief is the normal process of reacting to loss. Grief reactions may be felt in response to physical losses (for example, a death) or in response to symbolic or social losses (for example, divorce or loss of a job). With any type of loss, the person has had something taken away. As a family goes through a terminal illness such as cancer, many losses are experienced, and each triggers its own grief reaction.

Grief may be experienced as a mental, physical, social, or emotional reaction. Mental reactions can include anger, guilt, anxiety, sadness, and despair. Physical reactions can include sleeping problems, changes in appetite, physical problems, or illness. Social reactions can include feelings about taking care of others in the family, seeing family or friends, or returning to work. As with bereavement, grief processes depend on the relationship with the person who died, the situation surrounding the death, and the person's attachment to the person who died. Grief may be described as the presence of physical problems, constant thoughts of the deceased person, guilt, hostility, and a change in the way one normally acts.

Bereavement is the period after a loss during which grief is experienced and mourning occurs. It is the objective situation one faces after having lost an important person via death. The time spent in a period of bereavement depends on how attached the person was to the person who died, and how much time was spent anticipating the loss.

Mourning is the process by which people adapt to a loss. It is the public display of grief. While grief focuses more on the internal experience of loss, mourning emphasizes the external or public expressions of grief. Consequently, mourning is influenced by one's beliefs, religious practices, and society's rules for coping with loss.

Grief work includes the processes that a mourner needs to complete before resuming daily life. These processes include separating from the person who died, readjusting to a world without him or her, and forming new relationships. In order to separate from the person who died, a person must find a way to redirect the emotional energy that was given to the loved one. This does not mean the person should be forgotten, but that the mourner needs to turn to others for emotional satisfaction. The mourner's roles, identity, and skills may need to change to readjust to living in a world without the person who died. The mourner must give other people or activities the energy that was once given to the person who died in order to redirect emotional energy. Grief reactions may include:

- Numbness and disbelief.
- Anxiety from the distress of separation.
- A process of mourning often accompanied by symptoms of depression.
- Eventual recovery.
- Grief reactions can also be viewed as abnormal, traumatic, pathologic, or complicated. Some people may require psychological assistance for prolonged or abnormal grief reactions.

People who are grieving often feel extremely tired because the process of grieving usually requires physical and emotional energy. The grief they are feeling is not just for the person who died, but also for the unfulfilled wishes and plans for the relationship with the person. Death often reminds people of past losses or separations. Mourning may be described as having the following three phases:

- The urge to bring back the person who died.
- Disorganization and sadness.
- Reorganization.

Because of the overlap between grief and mourning, with each influencing the other; it is often difficult to distinguish between them. One's public expression (ie, mourning) of the emotional distress over the loss of a loved one (ie, grief) is influenced by culturally determined beliefs, mores, and values.

Conclusion

Only a century ago, death was common at every age, and usually quickly followed the onset of disease or injury. Today, advances in medicine and public health allow most Americans to live into old age. But, with our longer lives there is an increase in the number of people living with, and dying from, chronic debilitating diseases such as heart disease, cancer, stroke and chronic obstructive pulmonary disease.

Because many Americans today live their last years with chronic illness, the end of life is often a prolonged, uncertain period of difficulty. For these people, neither prevention nor cure is ordinarily possible. Instead, these patients and their families have other concerns including management of pain and other symptoms and coordinating care among multiple providers and settings.

End-of-life care is often fragmented, painful, and emotionally distressing, with unnecessary transitions between healthcare institutions, community-based organizations and home care settings. Despite the advances of modern medicine and its ability to prolong life and often cure previously incurable diseases, death itself is ultimately not preventable. However, much of the suffering that may accompany the dying process is amenable to intervention and healthcare can be improved to ensure that the last months and days of life are lived as fully as possible and with dignity and choice.

Despite all the improvements achieved in West Virginia through the work of the West Virginia Initiative to Improve End-of-Life Care and the West Virginia Center for End-of-Life Care, much work remains to be done—progress can sometimes be discouragingly slow. Despite an extensive media and public-awareness campaign in 2000–2001, a follow-up study of the media portion of the project provided discouraging results, with the appearance that few of those polled remembered or were affected by the information presented. A similar media study performed in 2009 noted mixed results—a high number of persons with advance directives and a large percentage who believe in the importance of talking with family members and doctors about EOL choices—yet many remain unaware of the resources available in their state, and younger people especially seem to shy away from dealing with the subject (RWJF, 2008; Jack Canfield, 2010).

West Virginia has benefited from the work of the initiative and the center, which have provided substantive data and suggestions to the legislature and played an active role in West Virginia's legislative accomplishments. Media offerings like the December 2010 West Virginia Public Broadcasting Service program and the play *Mercy Machine*, which debuted in Morgantown in April 2011, may turn out to be more effective ways to reach people and help them think about the issues than other more traditional vehicles.

(Resource lists follow on next page)

West Virginia Resources

West Virginia Center for End-of-Life Care

<http://www.wvendoflife.org/>

Center for Health Ethics and Law & WV Network of Ethics Committees

<http://wvethics.org/>

Robert C. Byrd Health Sciences Center of West Virginia University

1195 Health Sciences North

P.O. Box 9022

Morgantown, WV 26506-9022

Phone 877 209-8086

FAX 304 293-7442

Resources & Links page contains links to legislations, publications, all related West Virginia service agencies and programs, as well as many national ones.

West Virginia Public Broadcasting

The Last Chapter: End of Life Decisions

<http://www.wvpubcast.org/television.aspx?id=17786>

National Resources

Center for Practical Bioethics

<http://www.practicalbioethics.org/>

Kidney End-of-Life Coalition

1527 Huguenot Road

Midlothian, VA 23113

804 794-3757

kidneyeol@nw5.esrd.net

<http://www.kidneyeol.org/index.htm>

Center to Advance Palliative Care (CAPC)

<http://www.capc.org/>

1255 Fifth Avenue, Suite C-2

New York, NY 10029

212 201-2670

capc@mssm.edu

National Hospice and Palliative Care Organization

<http://www.nhpco.org>

Hospice Patients Alliance

<http://www.hospicepatients.org>

Hospice Foundation of America

<http://www.hospicefoundation.org>

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(Post test begins on next page)

Post Test

Use the Answer Sheet following the test to record your answers. There are 39 questions.

1. In 1999 when the WV Initiative to Improve End-of-Life Care was formed, a survey among healthcare professionals found a majority believed such care to be:
 - a. Excellent.
 - b. Fair to poor.
 - c. Better than any other state's care.
 - d. Poor.
2. Today West Virginia has the highest percentage of citizens with some form of advance directive.
 - a. True.
 - b. False.
3. The West Virginia legislature has, since 1984:
 - a. Promulgated very few laws related to EOL care issues.
 - b. Done nothing to address the conflicts inherent in EOL care issues.
 - c. Enacted more than ten pieces of legislation to improve and clarify EOL care.
 - d. Enacted a new law every year on some aspect of EOL care.
4. Science has found a way to define **end of life**:
 - a. By using actuarial tables to predict how long a person has left to live.
 - b. With precision.
 - c. As a process that includes a variety of transitions that accompany aging.
 - d. By means of statistics.
5. Half of Americans who live to age 85 have major memory loss in their final years.
 - a. True
 - b. False
6. The Patient Self-Determination Act of 1991 requires healthcare institutions to:
 - a. Allow inpatients to choose single rooms when they are hospitalized.
 - b. Offer balanced menus from which inpatients can choose their own preferences.
 - c. Allow a patient to sign out against medical advice.
 - d. Ask all adults being admitted as inpatients whether they have an advance directive.
7. A basic tenet of hospice care is:
 - a. The belief that death is the natural conclusion of life.
 - b. Delivery of care by one specialized healthcare professional.
 - c. That pain control interventions must consider the potential for addiction.
 - d. That a hospital is the best place for end of life care.

8. Palliative care:
 - a. Manages the needs of patients who have progressive, incurable illness.
 - b. Designates one “pal” who represents the patient in making decisions.
 - c. Is provided by one healthcare professional who knows the patient well.
 - d. Follows a plan that is designed to fit all patients equally.
9. Guidelines for quality palliative care developed by the National Consensus Project (2004, 2009) are based on:
 - a. Medicare and Medicaid benefits.
 - b. Input from the Joint Commission.
 - c. Available scientific evidence and expert professional opinion.
 - d. Intensive surveys of professional nurses and physicians.
10. Hospice care:
 - a. Is home care for the elderly.
 - b. Focuses on patients in the last six months of their lives.
 - c. Is always provided in a special hospice facility.
 - d. Is sometimes expensive but considered desirable for those who can afford it.
11. Hospice care is centered on:
 - a. The whole family.
 - b. The patient.
 - c. The caregiver.
 - d. The physician.
12. The services of the interdisciplinary hospice team:
 - a. Continue as much as a year or more after the death of the patient.
 - b. Are managed either by the hospice director or the patient’s personal physician.
 - c. Can never be utilized again even if the patient recovers only temporarily.
 - d. Include meal preparation and housekeeping.
13. Medicare certifies more than 90% of hospices in the United States to provide:
 - a. Services for the dying patient only.
 - b. Hospital services only for Medicare beneficiaries.
 - c. Limited services from among those offered to all Medicare beneficiaries.
 - d. A full range of services for the dying patient and the family.
14. The Medicare hospice benefit does not cover:
 - a. Medical equipment.
 - b. Speech therapy.
 - c. Treatment intended to cure the illness.
 - d. Grief counseling.
15. Breaking bad news is a task that:
 - a. Is best done quickly, with surgical precision.
 - b. Is complex, requiring good communication skills.
 - c. Should be done by a supervisor who can be professional but detached.
 - d. Is the job of the staff mental health specialist.

16. The palliative care of seriously ill or dying children:
 - a. Could be likened to treating small adults.
 - b. Requires special attention to medications due to toxicities associated with specific periods of childhood development.
 - c. Cannot be combined with curative treatment.
 - d. Involves hospice care in more than half of all pediatric patients.
17. When parents have home healthcare support for a child at the end of life:
 - a. The child may not need to be admitted to the hospital as often.
 - b. They have chosen home care and rejected hospitalization.
 - c. They are turning over control to the healthcare worker.
 - d. They are risking more intense feelings of grief when the death does occur.
18. Children who have advanced cancer:
 - a. Are welcomed into most hospice programs.
 - b. Generally have a wide array of palliative services available to them.
 - c. Often die while still in active treatment if they are in the hospital.
 - d. Are not usually eligible for clinical trials or stem cell transplantation.
19. Adults need to consider the child's developmental stage when talking about death:
 - a. Because it is the most important influence on a child's understanding.
 - b. Although it is only one of several things to consider when speaking about death.
 - c. So they can gear their presentation to it and avoid the need for repetition.
 - d. To decide when it is useful to compare death to sleep.
20. When planning the mourning rituals following a death:
 - a. Children should be excluded to avoid making them feel sad or frightened.
 - b. The plans should be allowed to unfold without discussing them in advance with children.
 - c. Whatever their level of grief, parents are the only ones who can attend to children's needs.
 - d. Children should be encouraged to participate in the planning.
21. Religious explanations about death must reassure young children that they themselves are safe.
 - a. True
 - b. False
22. Cultural competency is a term that refers to:
 - a. An understanding of community standards.
 - b. A broad familiarity with the arts.
 - c. The ability to talk about health concerns without cultural differences getting in the way.
 - d. A characteristic of those who have at least a college education.
23. When working with non-native English speakers in a bereavement situation:
 - a. The use of a trained medical interpreter is recommended.
 - b. A bilingual staff member is generally adequate as an interpreter.
 - c. The patient's family is the best choice for interpreting.
 - d. Do your best to be understood—after all, in this country people should be able to speak English.

24. Advance planning for end of life should ideally be done:
- When a potentially fatal disease is diagnosed.
 - When hospice care begins.
 - Before it is needed.
 - When the family can be gathered and consulted.
25. West Virginia law recognizes two types of written advance directives:
- Last will and testament.
 - Medical power of attorney and living will.
 - Living revocable trust and promissory note.
 - Promissory note and living will.
26. Physician Orders for Scope of Treatment (POST) forms:
- Do not need to be signed by a physician.
 - Can be used in conjunction with advance directives and DNR cards.
 - Replace advance directives but not DNR cards.
 - Replace advance directives and DNR cards.
27. Health providers can initiate discussions about advance planning when:
- The patient appears to be in deep denial.
 - The patient has been told about prognoses or treatment options that have poor outcomes.
 - There is a likelihood that the patient will be transferred to another facility.
 - The family is not supporting the patient.
28. Transitional care planning:
- Is essential to ensure quality of care during movement from inpatient to home care.
 - Is best delivered by one designated professional who understands the situation.
 - Can best be accomplished by the patient's family independently.
 - Can be successfully directed by the patients themselves.
29. In determining whether a spouse or caregiver can handle home care:
- It is important to choose a woman because they are more empathetic.
 - You must consider the length of the caregiver's relationship with the patient.
 - Rule out anyone who has a fulltime job outside the home.
 - It is necessary to assess the family's motivation and ability to provide care.
30. Antidepressants are seldom prescribed for cancer patients because their depression is not considered treatable.
- True
 - False
31. When patients are no longer able to swallow pain medicine:
- They are in the final hours of life and it is no longer needed.
 - The pain really cannot be controlled no matter what is done.
 - It can sometimes be placed under the tongue or administered by patch.
 - Giving opioids may cause death to occur sooner.

32. According to World Health Organization pain relief ladder, adjuvant drugs are:
- Employed along with pain medications from the outset of pain.
 - Medications usually used for conditions other than pain that may enhance analgesia.
 - Medications added to address the anxieties of the caregiver or family.
 - A substitute for pain medications that have become ineffective.
33. West Virginia physicians have encountered few problems surrounding the prescription of opioids.
- True
 - False
34. When fluid builds up in the airways, causing death rattle:
- Give medications to decrease saliva via patches or infusion.
 - Remove the airway fluid with suction.
 - Increase pain medications.
 - Increase food and fluids to stimulate natural function.
35. To control the delirium that is common during the final days of life:
- Increase the dosage of current medications.
 - It is important to find and treat the cause.
 - Take no action as it is to be expected.
 - Withhold fluids for up to 24 hours.
36. In the final hours, comfort measures may include:
- Touching.
 - A heating pad.
 - Favorite foods.
 - Conversation.
37. After the patient has died:
- Call 911.
 - Ask family and others to leave the room immediately and contact the authorities.
 - Ask what customs or rituals are important to the patient and family.
 - Cover the face of the deceased and leave the body in the position in which death occurred.
38. Bereavement is:
- When death nears and the family becomes emotional.
 - Subjective and can occur at any time.
 - A period of one year following a death.
 - The period after a loss when grief is experienced and mourning occurs.
39. Mourning is:
- The internal expression of grief.
 - The public display of grief.
 - Highly individual and unrelated to society's rules.
 - Subject to a commonly accepted set of expectations.

(Answer sheet follows on next page)

Answer Sheet

West Virginia: End of Life Care

Name (Please print your name): _____

Date: _____

Passing score is 80%

- | | |
|-----------|-----------|
| 1. _____ | 29. _____ |
| 2. _____ | 30. _____ |
| 3. _____ | 31. _____ |
| 4. _____ | 32. _____ |
| 5. _____ | 33. _____ |
| 6. _____ | 34. _____ |
| 7. _____ | 35. _____ |
| 8. _____ | 36. _____ |
| 9. _____ | 37. _____ |
| 10. _____ | 38. _____ |
| 11. _____ | 39. _____ |
| 12. _____ | |
| 13. _____ | |
| 14. _____ | |
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| 21. _____ | |
| 22. _____ | |
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| 24. _____ | |
| 25. _____ | |
| 26. _____ | |
| 27. _____ | |
| 28. _____ | |

(Course evaluation follows on next page)

Course Evaluation

Please use this scale for your course evaluation. Items with asterisks (*) are required.

5 = Strongly agree

4 = Agree

3 = Neutral

2 = Disagree

1 = Strongly disagree

- *1. Upon completion of the course, I was able to:
- a. List the main components of the Patient Self-Determination Act.
 5 4 3 2 1
 - b. Compare and contrast palliative and hospice care.
 5 4 3 2 1
 - c. Outline the main issues associated with end-of-life care in children.
 5 4 3 2 1
 - d. Explain the process of advance care planning.
 5 4 3 2 1
 - e. Identify treatment options for common symptoms seen at the end of life.
 5 4 3 2 1
 - f. Discuss the importance of supporting bereavement, mourning, and grief.
 5 4 3 2 1
- *2. The course was written in a way that facilitated my learning.
 5 4 3 2 1
- *3. This course was free from commercial bias.
 5 4 3 2 1
- *4. The course met my continuing education needs.
 5 4 3 2 1
- *5. The material presented was supported by evidence.
 5 4 3 2 1
- *6. The author avoided the use of anecdotal information as the main source of material.
 5 4 3 2 1

*7. The course was free of product promotion.

- Yes No**

** If you answered no, please answer #8.

8. Was product promotion the sole purpose of the presentation?

- Yes No**

*9. It took me 60 minutes per contact hour to complete the course, test, and evaluation.

- Yes No**

** If your answer was no, how long did it take?

10. My professional educational level is (check one):

Nursing

- Nurse Aide LVN/LPN RN (diploma) RN (AD)
 BSN MSN Nurse Practitioner/Advanced Practice Nurse
 PhD/DNSc

Therapy

- OT Aide COTA OT MOT OTD
 PT Aide PTA PT MPT MSPT DPT PhD

Other (please specify): _____

11. I heard about ATrain Education from:

- Search engine Advertisement
 Government or Board website Returning customer
 Friend Publication (Magazine, etc.)
 Other _____

12. I found the ATrainCEU.com website easy to use:

- Yes No

13. Comments or suggestions (optional): _____

(Registration on next page)

Registration Information

Please answer all of the following questions (*required).

* Name: _____

* Address: _____

* City: _____ State: _____ Zip: _____

* Phone: _____

* Professional Designation: _____

* License Number and State: _____

Please email my certificate: Yes No

Email (required if you want your certificate sent by email): _____

(If you request an email certificate we will **not** send a copy of the certificate by US Mail.)

Payment Options

You may pay by credit card or by check.

Fill out this section only if you are **paying by credit card**.

4.5 contact hours: \$19

Credit card information:

Name _____

Address (if different from above): _____

City: _____ State: _____ Zip: _____

Card type: Visa MC American Express Discover

Card number _____ CVS # _____

Expiration date _____

Test Completion and Mailing Instructions

1. Complete all forms:

- Answer Sheet
- Evaluation Learning Activity
- Registration Form (this page)

2. If you are **paying by check**, prepare a check for \$19 made out to ATrain Education, Inc.

3. Mail the completed forms and your payment to:

ATrain Education, Inc
5171 Ridgewood Rd
Willits, CA 95490

When we receive your forms and payment, we will mail (or email, if you request it) your certificate of completion. If you have any questions or concerns, please call or contact us at Sharon@ATrainCEU.com. And thanks for taking the ATrain!