A NATIONAL EPIDEMIC

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Course Material valid through 12/2014

We Want You To Learn! ©
A little more tired at close of day;
A little less anxious to have our way;
A little less ready to scold and blame;
A little more care of a brother’s name;
And so we are nearing the journey’s end,
Where time and eternity meet and blend.
And so we are faring adown the way
That leads to the gates of a better day.
A little more laughter, a few more tears,
And we shall have told our increasing years.
The book is closed and the prayers are said,
And we are part of the countless dead.
And so we are going where all must go,
To the place the living may never know.
Thrice happy if then some soul can say,
“I’m better because he passed my way.”
– Rollin J. Wells

The transition from life can be every bit as profound, intimate and precious as the miracle of birth.
– Bylock, 1994

You matter because you are you. You matter to the last moment of your life and we will do all we can, not only to help you die peacefully, but to live until you die.
– Saunders, 1994

Even though I walk through the valley of the shadow of death, I will fear no evil, for you are with me...
– Psalms 23:4

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About the Author/Editor

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Instructional Objectives

Upon completion of this course, the learner will be able to:

1. Define and characterize end-of-life care.
2. Compare and contrast hospice with end-of-life care.
3. Relate historical developments of the hospice movement.
4. Tell how end-of-life care fits within the continuum of the healthcare delivery system.
5. Identify the members of an interdisciplinary team usually involved in holistic end-of-life care.
6. Explain the role of bereavement services in end-of-life care.
7. Delineate the process for initiating a comprehensive treatment plan.
8. Summarize components of the initial assessment for end-of-life care.
9. State the role of palliative care and symptom management in end-of-life care.
10. List symptoms associated with end stage disease for each body system.

11. Outline strategies to meet the nutritional needs of a person in the end stages of life.
12. Summarize interventions that are useful in managing pain in a person having a terminal condition.
13. Name strategies to maintain good skin integrity.
15. Explain how the oxygenation needs of the terminal person can be met.
16. Name ways to implement therapeutic touch in a family system.
17. Define strategies to communicate effectively with client systems about death and dying.
18. Enumerate community resources for caregivers and families of terminally ill clients.

Purpose and Goals

It is not only the final event of death the healthcare professional must learn to deal with, it is the entire process and the complex experiences that dying individuals, their families, friends and all others involved must go through. The goal of this course is to increase awareness to a fine blend of sensitivity, insight and knowledge of the end-of-life process. This course will enhance nurses in every area of expertise.

Introduction

End-of-Life Care: What is it? How does it relate to life? The following quote reiterates the notion that death is simply another dimension of life – a transition of living. "You matter because you are You. You matter to the last moment of your life; and we will do all we can, not only to help you die peacefully, but to live until you die." – Saunders, 1994.

This perspective of death as a major life transition should be the focus of end-of-life care for a client (patient) in the last stages of life. The goal of end-of-life care is to deal more effectively with another major life transition: that is, dying.

This continuing education course focuses on the activities of health professionals that are involved in providing end-of-life care. For this course, end-of-life care is defined as assisting and providing support to a person who is in end stage disease process, resulting in the length of life being limited. The term “family system” is broad and encompassing: it includes the client’s significant other(s), immediate and extended family members, friends, and in some instances even the community. Each person defines who is included in his or her family system, and this group will vary from person to person. End of Life care often is used synonymously with the term “hospice care,” and the two are interchanged in this continuing education program. Both terms refer to caring for individuals who are in the final stage of life. However, the hospice care model is a philosophy of providing holistic, meaningful, and individualized care that fits the particular needs of the Client System: a dying client and his or her family system.

Health professionals in general, direct caregivers in particular, are in an ideal position to assist, and even express perspectives to, a person in their care that a layperson often may not be able to. Opportunities for meaningful interactions can be especially evident when administering personal care to the client in his or her home. A certain intimacy can be established while assisting a person with the usual and ordinary things of life such as preparing meals, doing housekeeping activities, and completing personal care. Before proceeding on to the specific components of terminal care for a dying person, an overview of the origins, philosophy and approaches of hospice care is in order. The hospice model is useful in developing a meaningful and effective plan of care for a person needing terminal care.

Hospice Care: A Philosophy for End-of-Life Care

The hospice model focuses on administering terminal care to the dying person. This model comprises a team of caregivers – professionals, paraprofessionals, auxiliary personnel, volunteers, family, friends, (in some cases, even the community) – who provide services to the dying person and his or her family system. The term hospice comes from the Latin word “hospes,” meaning both “guest” and “host.” In medieval times, a
Hospice was used to describe a place of shelter and rest for weary, sick travelers and for pilgrims who were pursuing long journeys. Mostly operated by religious orders, hospices often were aid stations located along the roadside en route to the Holy Land to be used by the Crusaders in need of care. Later, in the late 1800s, the Irish Sisters of Charity opened a hospice in Dublin. Subsequently, this group of nuns opened another facility in London that was designated as a “home for the dying” or “for persons on life’s final journey.” Today, the term hospice refers to a coordinated program of compassionate care for people with terminal illnesses and their families. The multifaceted care is provided to the family by a team of health professionals and lay volunteers.

The modern hospice movement had its beginnings in England under the leadership of Dame Cecily Saunders who was a nurse, social worker, and physician. In the late 1940s, she sat at the bedside of a dying man and learned from him about death and dying. He related how and where he preferred to spend his final days, and she attempted to fulfill those last wishes. Based on this experience, Dame Saunders’ vision began to take shape of a special home in London for the dying that would help one to have the type of death that the person desired.

From 1958 to 1965, Saunders worked at St. Joseph’s Hospice in London. Here she learned management of distressing physical symptoms, counseling skills, and the importance of spiritual care to ease the suffering of the dying and their families. Subsequently, she organized St. Christopher’s Hospice, an inpatient care program for the terminally ill. She also initiated continuing education programs to teach nurses, physicians, social workers, chaplains, and volunteers to work together to improve the dying person’s quality of life.

The first hospice in the United States was established in Connecticut in 1974. Similar programs spread throughout the country. Currently, in the United States, most communities have some type of hospice program that is designed to meet the needs of the dying person. In the early days of these programs, for the most part, patients who used hospice services had a diagnosis of terminal cancer. Today, however, clients of hospices have a variety of diagnoses. In general, if a person’s disease runs its expected course, the average life expectancy of hospice clients is measured in months, as opposed to years. For instance, hospice care recipients may have end stage cardiovascular disease, kidney or liver failure, neuromuscular disorders, adult failure to thrive, chronic obstructive pulmonary disease, cancer, acquired immunodeficiency syndrome (AIDS), or genetic conditions that are incompatible with life. Likewise, clients are of all ages, from the very young infant to centenarians.

Hence, health professionals will need to be familiar with the particular diagnosis of each client, in regard to anticipated developmental level, physiological changes, symptom management, and pharmacotherapeutics. This continuing education course does not specifically address each of those diagnoses or physical conditions. Rather, general concepts related to terminal care will be presented. The health professional is encouraged to seek more detailed, diagnosis-specific information from other texts. A section in this program will examine, in some detail, strategies to communicate more effectively with children who are dying.

The reader also should be aware that terminal care might not necessarily involve a client that has been admitted to a hospice agency, per se. Rather, terminal care may be administered to patients who are in the hospital or long term care facility, or it may be for a person that the nurse is case managing. Hospice agencies in particular, however, provide services that are reimbursed by third party payers, such as insurance companies, Medicaid or Medicare. Therefore, hospices, whether for-profit or not-for-profit entities, tend to be highly regulated and often are required to offer services within certain parameters. Medicare requires that two physicians certify that the patient, if their disease has typical progression, has six months or less to live. Medicare now realizes, that physicians are not able to so finely determine the number of months a person lives. Textbooks that discuss terminal care generally set the time frame from six to twelve months prior to death. Even though the terms hospice care and terminal care are interchanged herein, the reader should consider the overall content from this frame of reference.

Holistic Client-System Care

Not all care provided by hospice is for the dying person (client). The hospice model offers a holistic approach to care that focuses on the family system as well, broadly defined as all individuals a client identifies as important or supportive. This group often extends beyond what we have come to see as “the traditional nuclear family,” that is, a spouse, children, parents and siblings. In some cases the significant other may be of the same gender, or a fellow member of a commune or seminary. With the hospice model, generally one person is designated as the primary caregiver. This may or may not be a health professional. Sometimes it is a family member or community volunteer. Often, though, the primary caregiver is a health professional who may be referred to as the case manager. In essence, primary caregivers are responsible for arranging and coordinating the client’s care.

Hospices offer diverse services depending on the needs of residents in their market area and the skills that can be provided by their employees. Some hospices offer services to clients having a particular diagnosis, while others provide for a range of clients or a specific age group. For example, one may find in metropolitan areas a hospice program that specializes in the care of people having a diagnosis of cancer. Or, another may only provide services to children or only to adults infected with the HIV virus (AIDS). Most hospice programs in smaller communities tend not to restrict admission based on clients’ diagnoses or age. Generally, these hospices offer a range of services to all age groups diagnosed as having a terminal illness, with a life expectancy of less than six months.

A Continuum of Care Provided in Diverse Settings

Where is end-of-life care provided? Hospice care can be delivered in a variety of settings, including the home and acute care settings as well as other community-based healthcare settings. In the last 30 years, the principal setting for hospice care in the United States has shifted from the acute hospital and long-term inpatient settings to the home.
Part of the reason for this shift can be attributed to the consumer movement and partly to escalating healthcare costs. Policy makers note that the greatest costs for healthcare are incurred in the last two to four months of life; that is, during the end stage of disease when terminal care is needed. In addition to controlling escalating healthcare expenditures, a major reason for offering terminal care in the home is to allow one to spend his or her final days with dignity, in optimal comfort and familiar surroundings. For most people “home” is as we usually know it to be: the traditional house or apartment. However, for some, “home” may be an assisted living facility or a skilled nursing facility where more extensive specialized care is readily accessible.

Short-term (interval) inpatient care, such as a hospital, also may be where terminal care is provided in some cases. For example, some hospice programs, in addition to providing care in the home, may also have a freestanding inpatient unit. Here, a terminally ill person can be admitted from the home for short-term management of symptoms, such as pain or nausea. The overall goal always is for the person to return home so that the symptoms can be managed or controlled.

With end of life care, such as that provided by an organized hospice service, a continuum of care is promoted. In other words, services continue uninterrupted for a client even when there are changes in the care setting. Be it in the home, hospital, extended-care facility, or hospice inpatient unit, the client’s care continues to be offered by the same team and in a holistic manner. That is the philosophy and mission of the hospice model. This model, too, should guide health professionals when caring for a terminally ill client regardless of the setting or situation.

**Respite Care**

Respite care for a terminally ill person’s family is another service offered by many hospice programs and is considered by some to be part of end of life care. Respite services enable the caregiver(s) for a dying person to have a reprieve from the demands of 24-hour care. Medicare benefits allow for periods of five days of respite care. In some cases intermediate beds provided by a hospice program may be used for a client to offer respite services to family, when no other alternative is available to them. To reiterate, the focus of hospice care and End of Life care is on maintaining quality of life for the family system as a whole, while promoting a peaceful death for the terminally ill person. Physical, psychosocial and spiritual needs of clients and families are addressed in a holistic approach. These models of care use an interdisciplinary approach to provide care and include physicians, nurses, social workers, chaplains, therapists in various disciplines, family counselors, volunteers, and the community as a whole.

End of Life care using the hospice model ideally continues after the client’s death. Bereavement follow-up services often are offered by counselors who are prepared to assist the family system with the grieving process, recognize individuals with abnormal grief responses, and coordinate appropriate treatment interventions for those in need. One hospice caregiver describes the holistic End of Life care that he provides to a client system in these words: “I deal with things on a daily basis and forget about the fact that someone is dying. This is easiest for the client. Family members, especially the children of older parents, seem to have difficulty talking about death with their loved ones. That is where I, as a direct caregiver, can best assist them. I am there, performing my routine activities. These natural situations offer a comfortable opportunity for the individual family members to discuss their concerns about what is happening to their loved one, question what I am doing, communicate their concerns and feelings to me and each other.”

**Initiating End-of-Life Care Services**

The provision of terminal care to a client generally begins with a referral from the primary care physician where the family care plan is started. Other health professionals, a client, family member, or clergy may also make initial contact. For home health agencies and organized hospices, the client must first obtain a physician referral before services can be initiated by the agency. A physician referral is critical for the agency to be reimbursed for its services by Medicare, Medicaid or another third-party payer such as an insurance company or managed care provider. (Figure 1) Ideally, upon receiving the referral in the agency, a nurse or social worker makes a visit to the hospital to begin an initial assessment – before the client is discharged. This action goes a long way to assure a continuum of integrated care for the client. In most circumstances, frequently, the initial visit occurs in the client’s residence after he or she has been discharged from the hospital. Consequently, inadequate information and miscommunication can result in gaps.
in care for the client and frustration for all involved.

**Client System Assessment**

Regardless of where the initial visit takes place, the nurse or social worker explains the End-of-Life care services that are offered by the hospice program to the client and family. Generally a discussion is encouraged as to the most appropriate services for this particular case. If the client elects to receive services and is able to do so, he will sign all of the essential consent forms. If the client is unable, a family member will need to complete them.

Once informed consent has been obtained, an intake assessment is conducted. Generally a nurse does this. In order to develop a comprehensive and meaningful plan of care, it is important to have the client and family tell their story of the illness and describe significant events in their life history. They also need to tell how the illness of the client is impacting their everyday lives and the meaning of the illness to the family as well as the terminally ill person. From this assessment data, the health professional can identify the family’s particular needs and expectations in regard to terminal care for their loved one; or, in the case of the client, his or her particular wishes regarding this time of life. Subsequently, the team consisting of the client, the family and healthcare providers implement the plan that addresses physical, psychosocial, and spiritual needs of the client system having a member with a terminal illness.

**Planning the Care: An Interdisciplinary Approach**

Hospice, or end-of-life care, generally is available around the clock, seven days a week. Particular services that are to be administered are coordinated with the client, family, primary care physician, and interdisciplinary team members such as the nurse, social worker, chaplain, physical therapist, and nutritionist. For home care and hospice agencies, required services are regulated by state licensure requirements and Medicare/Medicaid certification guidelines. With the hospice model, each type of caregiver offers the client system something that no one else can. For instance, intermitent nursing care is given by or under the supervision of a registered nurse.

A nurse case manager generally manages and supervises the family system’s care plan for the terminally ill client. During regularly scheduled visits to the client’s home, the nurse provides direct physical care, monitors the disease process, assesses the presence and severity of symptoms (e.g., pain, dyspnea, urinary and gastrointestinal disturbances), monitors response(s) to medications, and coordinates other specialty interventions (e.g., physical therapy, oxygen therapy, radiation therapy, counseling services). The nurse case manager also provides specific instructions regarding changes in the care plan, offers emotional support, supervises auxiliary nursing personnel and lay volunteers, and serves as a liaison with the physician and other team members.

The primary care physician (who may also be the medical director of a hospice agency) is actively involved with office visits, home visits, inpatient care, phone consultation, and interdisciplinary discussions regarding the client’s care plan. The physician also must order medications and specialty services and therapies, as well as durable medical equipment for symptom management if these are to be reimbursed by third party payers. Upon consultation with the primary physician, referrals are made if specialists are needed to assist in managing symptoms, such as gerontologists, radiologists, oncologists, gastroenterologists, pulmonologists, physical therapists, respiratory therapists, and psychiatrists. Subsequently, visits with consulting physicians and other health professionals are included in the interdisciplinary plan.

The social worker on the team assesses for the need to make other referrals, then coordinates the use of community resources with the client system and caregivers. This individual also assists the client and family to deal with issues of loss, current and future role changes for the client and individual family members; communication problems, financial and legal concerns, and social and emotional isolation. They also assist in funeral planning and prebereavement assessment.

Any type of healthcare program that promotes holistic services must address the spiritual and religious needs of its clients. Likewise with hospices and in terminal care, chaplains have an important place on the team. Their services are provided as requested by client, family or caregivers. The chaplain should be readily available to address the client system’s spiritual and religious concerns, and to act as a liaison for them with other clergy in the community and with other caregivers on the team.

Volunteers from the client’s community, paraprofessionals, and auxiliary personnel, in collaboration with health professionals, all have a role in offering a comprehensive and coordinated program of terminal care to the client system. For instance, volunteers may provide personal care or homemaking/housekeeping services. Or, the volunteer(s) may run errands, provide transportation for an outing for the client or a family member, and make visits to the home to provide emotional or domestic support. Paraprofessionals, such as certified nursing assistants (CNAs) assist with a client’s activities of daily living (ADLs).

With careful planning and effective use of the skills of each person, the team should empower the client system to spend their final days together and have the kind of death they desire.

**Implementing Palliative Care**

Palliative care and symptom management are the core of end-of-life care for a client experiencing end stage disease symptoms. Underlying the hospice model is a guiding philosophy that palliative care and symptom management should neither hasten nor postpone death. Rather, the interventions should affirm life. This belief reinforces the idea that dying is a normal and transitional life process. Hence, palliative care and symptom management in a dying person are directed toward promoting a high quality of life, relief of suffering, and supporting a peaceful death. They encompass the active and total care of people whose disease is not responsive to curative treatment.

Diagnostic procedures and special treatments such as chemotherapy, radiation, nutritional augmentation, pharmacotherapies, and in some cases even surgery, may have a place in palliative
care. These interventions are ordered by the physician if the benefits in providing relief of symptoms outweigh the disadvantages of not having it. The goal of any intervention in palliative care is to improve the quality of life for the person by managing the symptoms as opposed to controlling or curing the disease. The key question with each intervention is "what is the goal". How will this information (diagnostic test) change what is being done? If it is simply for the sake of knowledge, it serves no purpose, and if fact, can complicate the care.

Since researchers and health professionals are acknowledging that individuals with end stage illnesses and their families have special needs, a new specialty field continues to evolve. Palliative care is also recognized as a specialty in the United Kingdom. More specifically, nursing specialties in palliative care and symptom management are included with certification in oncology, hospice and home care. Hospice and Palliative Nursing Association (HPNA) offer recognized certification to all levels of nursing practice. See www.hpna.org for details.

Palliative care focuses on the relief of suffering when the underlying disease cannot be cured. Suffering is described as a state of severe distress that often is associated with events that threaten a person’s intactness as a human being. Hence, suffering is viewed more broadly than simply experiencing physical pain. Rather, the whole person experiences suffering: having pain in the mind and spirit as well as one’s body. The hospice model for providing holistic end of life care, in turn, attempts to palliate or relieve the sources of physical, psychosocial, and spiritual distress in order to allow for a quality death experience.

This concept of suffering raises concern about use of the label “routine end of life care,” especially when caring for clients who are dying in the hospital or long-term care facility. Since suffering is multifaceted and varies from individual to individual, it is important to acknowledge that there is nothing routine about end of life care. Care should be tailored to meet the needs of a particular client system. End of life care focuses on symptom management, which involves active listening, careful assessment, skilled intervention, and constant reevaluation on the part of the healthcare team.

Moreover, the physical symptoms will vary with different diagnoses, affected body systems, progression of the end stage disease, and impact of these factors on the individual person. For example, 62%-86% of people with advanced cancer experience pain at some time during their illness. But other conditions produce pain as well, including heart disease, AIDS, decubitus ulcers, and neuropathy. Different interventions may be needed to manage the pain experienced by different clients with different diseases.

In addition to pain, there may be other physical symptoms experienced by the client receiving terminal care. For example:
- Neurological symptoms including seizures, paralysis, or changes in mental status such as lethargy, confusion, agitation, or hallucinations; sensory and perceptual changes (aphasias).
- Cardiovascular symptoms such as edema, syncope, hemorrhage, or angina.
- Respiratory symptoms such as dyspnea, shortness of breath, cough, or congestion.
- Gastrointestinal symptoms such as nausea, vomiting, anorexia and cachexia, constipation, diarrhea, prolonged or continuous hiccups.
- Genitourinary symptoms such as incontinence, retention or dysuria.
- Musculoskeletal symptoms such as weakness, fatigue, pathologic fractures, contractures and spams.
- Integumentary (skin and mucous membranes) symptoms such as pressure ulcers, ulcerative lesions, dry mouth, oral lesions, infections and pruritus.

Consequently, in addition to assisting with or providing routine activities of daily living during end of life care, special therapies may be ordered by the physician to relieve or manage symptoms. For instance, nutritional, physical, occupational, or speech therapy may be ordered for persons with a chronic disease or debilitating conditions to maintain a certain quality of life during the end stages of the condition. Such interventions, like the Hoyer lift, may also help to maintain a greater degree of mobility or enable one to participate in activities of daily living for a longer period of time. Medical supplies and durable medical equipment also can be helpful in palliative care and symptom management, such as hospital beds with special features; oxygen, intravenous, and enterostomy therapies; and wheelchairs and other comfort devices. In addition to improving comfort, durable equipment and medical supplies can help to provide a safe environment for the client as well as caregivers.

In the end stages of the disease process and during periods of crisis during terminal care, a registered nurse, licensed practical/vocational nurse, or certified nursing assistant may be available on a 24-hour basis in the home. As necessary, appropriate laboratory and diagnostic services can be ordered by the physician and administered by caregivers to manage symptoms, provide comfort, and improve the client’s quality of life during the final days.

Management of Specific Symptoms

Symptom management in many cases is the most important activity in providing terminal care to a client. Symptoms will vary from person to person, and his or her particular health problems or diagnosis. Likewise, the symptoms will change in intensity, frequency and duration as the disease progresses. Carefully listening to what the client is telling you, observing and assessing for changes from the baseline status, then intervening early on can go a long way to managing symptoms in the terminal client.

Symptoms encountered in end of life care that cause an intense degree of discomfort include nausea, vomiting, anorexia, pain, skin breakdown and decubitus ulcers, urinary and bowel irregularities, and respiratory problems. If these cannot be managed at home, short-term inpatient care is provided for symptom control, respite care, or end of life care (when death is imminent).

Although each discipline providing care to a client has its own area of expertise, assessment and interventions often overlap among the professionals when it comes to symptom management. For example, physicians and nurses, as well as volunteers, may have a role when it
comes to managing and controlling pain. The chaplain, likewise, is not the sole guardian of spiritual life and also has a role in pain perception and its subsequent management. Certified nursing assistants tend to spend more time in the home than do other professionals since they perform most of the personal care. In turn, CNAs may be privileged to glean special insight into the client’s physical, emotional, and spiritual concerns. All of these intrinsic factors can influence the perception of symptoms such as pain, and its management by the client and his or her caregivers. Hospice should NEVER give up on getting control of symptoms.

Pain Management

Pain management is an important component of end of life care. In recent years major contributions have been made to the nursing research literature regarding protocols for pain relief in end of life care. The holistic view of pain and its management includes attention on the part of the caregiver to physical, emotional, social, and spiritual needs. Adequate availability and doses of analgesics, including narcotics; around-the-clock scheduling; and the use of co-analgesics and other non-drug interventions have made the control of pain an attainable goal. Throughout the care process, the client is central in making decisions about pain management. Judicious use of prescriptive and non-prescriptive drugs can greatly enhance the quality of life by providing relief from pain and other discomforts such as nausea, vomiting, and diarrhea.

Analgesia includes not only drug therapy, but also non-pharmacological interventions such as imagery, massage, therapeutic touch, music therapy, and meditation. The goal of therapy is to keep the client comfortable, as defined by the client, without overly clouding mental and cognitive functions necessary to the client’s participation in the activities of daily life. Fears of addiction to narcotics frequently are a concern to clients and families as well as healthcare professionals. Thus, teaching about pain management and facilitating the expression of beliefs about the use of medications are critical interventions if these are to be used effectively in palliative care and symptom management.

The Agency for Health Care Policy and Research (AHCPR) has published guidelines for pain management in children and adults. It recommends helping the person establish goals for pain relief as well as teaching them how to rate their pain. There are a variety of pain rating scales that can be used to assess the perceived relative intensity of discomfort. (Figure 2) Overall, a pain rating scale can be compared to a thermometer in recurring temperature and should be used in a similar manner. Just as nurses intervene to control unacceptably high temperatures, so too should interventions be initiated to control unacceptably high pain ratings. Determine what level is acceptable to the patient.

It is important to document the person’s understanding of the pain rating scale and pain relief goal. That is to say, the client system should be involved in determining tolerable and desired pain level on a rating scale, and subsequently identifying appropriate intervention activities. For example, one commonly used pain scale uses a rating from one to ten, one indicating minimal discomfort and ten being extremely intense pain. A mutually agreed-upon goal (client system and nurse) in this case could be for the client to recognize early warning signs of discomfort (i.e., a rating of 2 to 3 on the scale). The client will act at that point, using relaxation breathing and focused imagery in order to prevent increased levels of discomfort. The family will help the client identify early warning signs of discomfort by observing for certain behaviors, specifically irritability and restlessness. If the pain exceeds a level of 5 on the pain scale, the nurse or caregiver will immediately administer the prescribed analgesic.

Measures of client comfort and function should be visible to caregivers as well as the client system on a documentation record, such as a bedside flow sheet specifically designated for rating pain. This information will provide an assessment of the success of the pain control regimen and also remind the caregiver that ratings above a specified number require intervention. Whether or not the agreed-upon goal has been achieved should also be routinely reported at the change of shift, along with other information about the person’s status such as vital signs. In fact, the American Pain Society suggests that pain rating be treated as the fifth vital sign (in addition

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![Pain Management Table and Diagram](image-url)

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End-of-Life Care Page 9
Bathing Comfort Measures

- Reduce pain/discomfort as much as possible
- Accommodate the client’s preferences (time, frequency, type, water temperature, room, soap, lotions, shaving equipment, clothing, etc.)
- Encourage client system involvement (e.g., spouse, trusted same-gender friend, etc.)
- Create a comfortable personal space (e.g., music, linen, plants)
- Protect privacy
- Avoid chilling of client
- Use comfortable/functional equipment (e.g., gentle shower sprays, padded seats/walkers, foot rests, towel-lined chairs)
- Explain what is happening/expected
- Talk in low voice
- Persuade rather than demand
- Consider client’s physical limitations
- Do not rush
- Give positive feedback

Figure 3

Skin Care

Intact skin is one of the most important body defenses. Good skin care, therefore, is a critical aspect of end-of-life care. Realize however, that hospice patients are usually nutritionally deficient. They are predisposed to develop skin breakdown due to poor nutritional state and immobility.

It is important to make the family unit aware of this challenge, so if/when skin breakdown occurs, they will not blame themselves for improper or neglectful care.

The treatment of pressure ulcers costs from $5,000 to $40,000 per lesion, not including costs related to lawsuits. The estimated national cost is more than $1.3 billion each year. More difficult to quantify is the degree of suffering, disability and pain inflicted on those who develop a pressure ulcer. Obviously, the most cost-effective approach is to prevent skin breakdown, as opposed to the treatment of pressure ulcers once they have occurred.

To protect clients, as well as caregivers from lawsuits, be sure that skin care is based on research rather than rituals. AHCPR decubitus prevention and treatment guidelines state daily baths may not be necessary for some clients. Current research indicates that moist skin is less prone to break down and heals faster than does skin that is dry. Dry, flaking or scaling skin actually increases the risk of developing pressure ulcers.

As part of end of life care, the skin should be cleansed at the time of soiling and at routine intervals. Frequency of skin cleansing should be individualized, based on a person’s needs and preferences. Avoid hot water and use a mild cleansing agent to minimize skin irritation and dryness. Care should be taken during the cleansing process to minimize the application of force and friction to the skin. Environmental factors can also lead to skin drying such as low humidity (less than 40%) and exposure to cold. (Figure 3)

Dry skin should regularly be treated with moisturizers. Harsh soaps and powders that dry the skin can further the damage associated with excessive bathing, which puts a terminal client at an even greater risk for skin breakdown. Soap is a powerful emulsifier of fats and lipids binding water from the skin. This mechanism promotes skin dryness. Soap tends to be mildly alkaline (pH 10-12), and its complete removal from the skin in a soap and water bath can be difficult. Most soaps, therefore, will alter the natural acidity of the human skin (normal pH is 4.5 – 5.5), which serves as an effective antimicrobial barrier. Leaving small amounts of soap on the body alters the skin’s acidity, thereby reducing its natural antimicrobial actions. Furthermore, previously used bars of soap can harbor microbes which may transmit disease-causing organisms from one bath to another. Soap used in routine bathing for terminal clients should, therefore, be a liquid antimicrobial solution, having a neutral pH, and containing skin moisturizers. Never use the same bar of soap on two different persons as this has the potential for cross-contamination.

Re-used supplies (even for the same client), such as soap bars, basins, towels
and washcloths also can become contaminated with gram-negative organisms that can be transmitted to the skin when bathing the person. Basins should be disinfected and thoroughly dried after use and before these items are stored between baths. Washbasins should not be used as emesis basins or stored next to bedpans or urinals, in order to prevent cross-contamination with disease-producing organisms. Adding oil to the bath water may be a good strategy to help reduce skin dryness. However, the oil residue can be difficult to remove from the skin after bathing, and is an ideal medium for prolific bacterial growth. This residue, in turn, can be a source for infection in clients with impaired skin integrity, as often is the case in the end stage disease process. Another common pitfall in skin care is not changing the bath water frequently enough. In this scenario, dirt removed from one part of the body subsequently is reapplied to other areas of the skin.

As for the best approach to care for skin ulcers, moist wounds heal faster and with less scar tissue than dry wounds. Physiologically, the scab formed by wound drying impedes the movement of epidermal cells in the healing process. Moist environments also enhance the synthesis of collagen in dermal repair. The AHCPHR does not condone the practice of excessive drying such as with heat lamps, exposure to air, alcohol, repeated cleansing with disinfectants, powders, and gauze dressing. These interventions deter healing and can cause even further skin damage. Prevention guidelines put forth by AHCPHR specifically advise against cleaning ulcer wounds with skin cleansers and antiseptic agents (i.e., povidone-iodine; iodophor; sodium hypochlorite solution (Dakin’s solution); hydrogen peroxide or acetic acid) because these substances are cytotoxic in nature. An easy-to-remember rule of thumb for skin care is, “Don’t put in a wound what you would not put into your eye.” Normal saline passes this test.

Routine skin cleansing should be accomplished with a minimum of chemical and mechanical trauma. Unfortunately, it is a common practice to debride wounds that should not have this procedure done.

The family and caregivers, as well as the terminal client, are often concerned about body odor (e.g., axillary, perineal, under breasts, between skin folds). Consequently, one finds the excessive use of scented deodorant products to combat or counteract the odor in persons with end stage diseases. Not only are many individuals sensitive to these products, but incomplete removal can lead to bacterial growth and skin lesions and fissures. Generally, the skin of a healthy person does not have an odor. Odor usually develops from bacteria proliferating in ‘old body perspiration’ that is not removed from the skin, and actually can intensify with the use of deodorant products that are not completely removed. With a end of life condition body odor may also be a component of the physiologic processes associated with the disease and/or dehydration. Therefore, routine gentle cleansing and drying as described in the previous paragraphs are the most effective strategies to deal with body odor.

Another important aspect of routine care is oral hygiene.

It is important to prevent problems before breakdown occurs in the mucous membrane, as this increases opportunities for infection. Routine oral hygiene consists of denture cleaning by gentle brushing or wiping with soft swabs and the use of a mild (neutral pH) mouthwash such as normal saline. Halitosis often occurs in the end stage of many disease processes. However, over-the-counter mouthwash products are contraindicated, as most of these products contain astringents or alcohol that can dry the mouth and be highly irritating to lesions or fissures in the mucous membranes. For those who have dentures, be especially aware of pressure areas in the mouth. Pressure areas often result from excessive weight loss, which contribute to changes in the shape and structure of the gums leading in turn to an improper fit of the denture plate. Improper fit can result in lesions and infection in the oral cavity. Patients that are unresponsive require oral care as well, consider how you feel with continual morning breath. Also many medications that are used to control respiratory secretions dry the mucous membranes, which adds discomfort. So oral care moistens the mouth and adds to comfort, yet can be done with limited amount of liquid to avoid issues with dysphagia. Oral care is also especially important in persons infected with the HIV virus, as opportunistic infections readily occur in the oral cavity.

Hair care is also part of skin care, and routine shampoos are an important comfort measure in terminal care. As with soap, the shampoo that is used should not contain perfumes or protein conditioners which can irritate the scalp. Care must be taken to prevent scalp and skin scratches when washing; then to rinse the hair thoroughly to remove soap residue. Conditioning can help to address scalp

### Assessment of Client’s Cognitive Status

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Normal response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Orientation to person ..........</td>
<td>Correctly states full name</td>
</tr>
<tr>
<td>Orientation to place ............</td>
<td>Correctly states complete home address, a current location</td>
</tr>
<tr>
<td>Short-term memory ..............</td>
<td>Correctly states requested facts, names primary clinician and person in prominent positions (e.g., President of U.S.)</td>
</tr>
<tr>
<td>Short-term recall ..............</td>
<td>Recalls three or four words/numbers, in sequence, after three to five minutes (e.g., 1; 5; 10; 20)</td>
</tr>
</tbody>
</table>

Figure 4
Symptoms of (possible) Impaired Cognitive Function

- Significant memory loss
- Risk-taking behavior (e.g., climbing over bed rails or trying to get out of wheel chair)
- Agitation, anxiety, belligerence
- Apathy, depression, “not being with it”
- Using non-typical language (e.g., cursing, use of sexually orientated words)
- Paranoia regarding self or family
- Impaired communication (e.g., rambling, words incongruent with affect)
- Confusion and restlessness (especially at night)
- Sleep disturbances
- Changes in behavior (e.g., exhibiting non-typical responses; incontinence)

Urinary Function Support

Changes in urinary excretory patterns often occur with terminal conditions, most often in the form of retention and/or incontinence. Essentially, over a 24-hour period fluid intake should equal output. Therefore, in terminal care an important nursing measure is the monitoring of the person’s intake and output, then implementing appropriate strategies to prevent and address urinary-related problems. When intake and output monitors are in place, it is important that these measures be recorded accurately (frequency, time, amount, color, odor, etc). Become familiar with the documentation forms used in each particular setting to ensure appropriate recording of client data. As with skin care, prevention of urinary problems is the best approach. One common cause for urinary retention is dehydration associated with not maintaining an adequate fluid intake. Addressing this situation requires some creativity on the part of the caregiver, especially in cases where a client has no appetite, or is disoriented or confused. (Figures 4 and 5)

Hydrating interventions should be clearly documented. This documentation can be invaluable in helping the hospice team hold steady to the stated wishes of the patient when others may guilt them about “starving her to death”.

Urinary retention is one of the most common problems encountered with terminal conditions, and can be due to a variety of causes including medication side effects, lack of exercise, anxiety, infection, bed rest, and physiological deviations/changes. Management of the problem usually is based on its cause. Therefore, careful assessment of the client is needed to note symptom patterns so that appropriate diagnostic and intervention measures can be instituted. The signs and symptoms of urinary retention include distension, pressure, burning and pain in the lower abdomen, pelvis and back areas, and not being able to void. In some cases the nursing interventions are as simple as ensuring privacy, and encouraging the client to stand, walk, drink more fluids and try relaxation techniques. In other cases, the person may need to be catheterized. The protocols for this procedure are beyond the scope of this course: the reader is encouraged to seek out a nursing skills text or practice and procedure manual for specific details on urinary catheterization.

Urinary incontinence is another common nursing problem in persons needing end of life care. Incontinence is categorized into two major categories – acute onset and chronic. For chronic incontinence, the onset usually is gradual; initially the person loses only one or two drops of urine occasionally. Gradually, the amount progressively increases to “larger accidents” occurring more frequently. The symptoms can span several weeks or even years.

The nurse should consider the causes of acute urinary incontinence whenever a previously continent person develops incontinence. The mnemonic DRIP can be useful to recall causes of acute incontinence.

Delirium/Dehydration: Dehydration can lead to confusion, which is associated with urinary incontinence, and may cause high urine concentrations that irritate the bladder and trigger uninhibited bladder contractions.

Retention: The bladder will usually begin to leak when it gets to its maximum capacity.
Impaction/Infection: A large amount of stool in the colon places pressure on the bladder and interferes with normal emptying. Fecal impaction can also lead to bladder neck obstruction which may cause retention, and eventual bladder overflow. Infections also can cause swelling and pain in the urethra and bladder, which lead to the inability to void.

Pharmaceutical: Medications that are used to treat urinary tract infections (UTI) can lead to incontinence, as can numerous other drugs. The nurse is encouraged to become familiar with the side effects of all the drugs the person is taking, as well as the pharmacological effects and dosage of each. Remember to ask about over-the-counter drugs the person may also be taking since drug interactions are always a possibility.

Once the etiology of acute onset incontinence is identified, a treatment plan can be developed to treat the cause. A detailed list of interventions is beyond the scope of this course. The reader is encouraged to review medical texts for more information on the topics of urinary retention.

There are four types of established or chronic urinary incontinence, and each has its own cause and treatment approach. Therefore, a client needs to have an individualized evaluation and appropriate diagnostic testing to properly identify the type(s) of incontinence that may exist. Always remember, though, that regardless of the cause of urinary incontinence, routine meticulous skin care is critical to prevent breakdown and ulcers from occurring. Urinary incontinence also is the source of unpleasant odors. This can be attributed to high uric acid concentrations associated with dehydration, urinary tract infections, and inadequate removal of urine from the body. Residual urine remaining on the linen, especially rubber and plastic sheeting, disposable diapers, and pads used to protect bedding are especially problematic. Therefore, in addition to skin care the bed linen also should be changed frequently, thoroughly laundered with sanitizing agents, and rinsed completely.

1. Stress urinary incontinence is the involuntary loss of urine when coughing, laughing or lifting heavy objects. Although this type of incontinence most frequently is seen in women, men also may experience it following lower abdominal, prostate and bowel surgery. The most common cause of stress incontinence is hypermotility or displacement of the urethra and/or bladder neck during exertion. In these cases, abdominal pressure interferes with the ability of the urethral sphincter to remain closed and contain urine.

2. Urge incontinence is the involuntary loss of urine by a person while en route to the bathroom. Occasionally this condition is referred to as the “key in the door syndrome.” In these situations the urge to urinate gets stronger as the individual gets closer to home. By the time he or she puts the key in the door their bladder contracts uncontrollably and urine begins to leak. Urge incontinence is caused by involuntary contraction of the bladder muscle, much like the hiccups (i.e., contractions of the diagram forcing air to be forced uncontrollably from the lungs).

3. Overflow incontinence occurs when the bladder fills to capacity and the individual does not feel the urge to void. In these cases the bladder frequently leaks small amounts of urine (“dribbling”). This can be a tremendous source of discomfort for the patient, especially when they are actively dying. Overflow incontinence is associated with obstruction of the bladder neck which often occurs with tumors in the lower pelvic area, prostate hypertrophy, medications (such as benztrapine mesylate [Cogentin]; propantheline [Pro-Banthine]; tri-hexyphenidyl [Artane]) or neurologic conditions such as multiple sclerosis, strokes and seizure disorders.

4. Functional incontinence is due to impairment of physical or mental abilities other than a physiologic abnormality of the bladder. For instance, an elderly person may not be able to identify feelings associated with the need to void stemming from mental confusion associated with medications, an unfamiliar environment or a physical disability that can interfere with their getting to the bathroom.

A few comments are in order about the aged, the aging process and urinary incontinence that are relevant to terminal care. Growing old does not necessarily mean ‘growing into diapers.’ Nor is urinary incontinence considered to be a normal part of the aging process. However, when providing terminal care for an elderly person it is important to be aware of two “age-related” physiologic changes that occur with the urinary system. That is, one can expect to see a larger post-void residual urine and an elevated urinary output when the person is resting. Post-void residual is defined as the small amount of urine that remains in the bladder after voiding. This volume tends to be about 30-60 cc in a 20-year-old person but can be as high as 200cc in an 80 year old.

Large urinary residual places the person at a higher risk for developing urinary tract infections. Persons with higher residuals will need to void more often as they begin with the bladder having a greater amount of urine. For many older persons, therefore, an uninterrupted night’s sleep becomes only a memory due to an elevated urinary output when the person is at rest. Dependent edema in the lower extremities is filtered by the kidneys when at rest, resulting in “age peak” urine production. This requires that the older person get up several times during the night to void, and can pose safety hazards associated with disorientation, confusion and falls.

The AHCRP protocol for the clinical management of urinary incontinence in adults recommends that the preliminary treatment options should be the least invasive and least dangerous. For example, behavioral treatments (bladder training, timed voiding, prompted voiding, pelvic muscle exercises) should be used in conjunction with adjuvant therapies (biofeedback, electrical stimulation, vaginal cone insertion). However, these therapies are most effective in motivated persons who have a thorough understanding of their type of incontinence, its cause, treatment options, and goals of therapy. Individual participation is critical to behavioral approaches, which often take a long period of time to resolve symptoms. For this reason, less invasive approaches may not be as useful or effective in end of life care. Instead, more invasive measures (catheterization,
surgery) may be needed to treat chronic urinary incontinence.

**Oxygenation Support**

Persons in the end stage of a disease often have oxygenation needs, stemming from impaired respiratory function, that can further disrupt body homeostasis. Maintenance and restoration of homeostasis is accomplished primarily by optimizing oxygen supply, repaying any oxygen debt that may have accumulated, and decreasing the body’s demand for oxygen. Oxygen supply in the body can be optimized through volume resuscitation (fluid replacement), inotropic and vasopressor administration, optimal hemoglobin levels and arterial saturations. The decreased functional ability of the cardiac and pulmonary systems in terminal states determines the most appropriate intervention(s) to be used with a terminal client. Physical responses will vary due to physiologic changes associated with aging and the disease process.

When evaluating persons with chronic obstructive pulmonary disease (COPD) and the elderly, be sensitive to the fact that diagnostic parameters of optimal cardiac output and oxygen saturation may be different than for a ‘normal’ healthy person and depend on age. For a healthy elderly person, for instance, the cardiac output may be as much as 50% less than for someone who is younger. Therefore, volume resuscitation or pharmacological agents may not achieve the ‘normal’ result of 4-6 liters per minute in an older person.

Chronic disorders that affect pulmonary, cardiac or renal function also can affect one’s response to fluid administration and drug therapy. Elders and persons in congestive heart failure, for instance, may respond with worsening shock when fluids are administered. Nurses should therefore be aware that physical assessment findings might be better indicators of oxygen circulation (e.g., mental status, urine output, skin color and temperature) than laboratory values. For this reason, it is important to have baseline data with which to compare subsequent observations.

Tissue perfusion of oxygen can be impaired for many reasons. In addition to optimizing cardiac output with medication and fluids, another approach to improving oxygenation and tissue perfusion is administering oxygen. With the elderly, normal values may be lower on both of these indices. Likewise, in some chronic conditions, such as COPD and liver disease, these limits may be higher than “normal.”

Another approach to improving oxygen supply is to decrease the body’s demand. Generally in end of life care, caregivers will find that the elderly and critically ill have a decreased functional reserve; and thus are not in a state of physiological homeostasis. Every effort should be made to decrease oxygen demands of all the body systems. Nursing interventions to achieve this include keeping the person free from pain. Providing frequent rest periods interspersed with carefully monitored activity and having the CNA or family member assist with ADL’s reduces the oxygen deficit that these activities will normally produce. Refer to the section on pain management for nursing strategies. Repositioning, too, can make breathing easier and improve circulation (e.g., raising the head of the bed, supporting the back and neck, elevating the feet to an equal height with the pelvis). Other environmental factors, such as room temperature and humidity, also can affect respiratory efforts.

Insufficient oxygen can lead to feelings of anxiety; consequently, it should be treated to prevent a cyclical effect on cardiac and pulmonary efforts. Sometimes simple interventions such as allowing the client to speak to another person on the telephone, or having visitors in or out of the room, can do much to reduce the person’s anxiety. This, in turn, decreases the work of the cardiac and pulmonary organs. In other cases sedatives or anti-anxiety medications may be needed to keep the person more comfortable. Morphine has a direct effect on increasing bronchial size, decreasing anxiety, and reducing restricted breathing sensation. High or low body temperature shifts along with hypovolemia, hypervolemia and marked fluctuations in blood pressure also increase physiologic demands for oxygen. Efforts should be made to prevent these wide shifts through appropriate early interventions.

In brief, oxygenation needs in end of life care are of particular importance with the elderly and chronically ill because of their diminished reserve prior to the onset of this episodic event. Intravenous therapy and oxygenation techniques are important skills for nurses in this setting. For more specific details on those procedures the reader is encouraged to review texts on nursing skills and policy and procedure manuals of their employing healthcare facility.

**Nutritional Support**

An important aspect of end of life care is meeting the nutritional needs of the person. This aspect of care can pose special challenges to the caregiver as well as the family system. Associated with chronic and acute illnesses, aging and bed rest are a variety of gastrointestinal symptoms such as nausea, vomiting, anorexia, constipation, diarrhea, abdominal pain and cramping. For each of these symptoms there is a multitude of nursing and pharmacological interventions. For instance, for anorexia and nausea one could try offering small frequent feedings of food that the person enjoys; offering food at the temperature the person prefers; and, giving an anti-emetic medication before offering food. For constipation one could increase fiber in the diet; offer prune, pear and apple juice several times each day as these are also high in sorbitol; or administer stool softener or enema at regular intervals.

In many instances, the client is satisfied with his or her nutritional intake, but the family expresses their concern about that aspect of terminal care. Therefore, nutritional counseling is an integral part of terminal care. The overall goal of nutritional support in a person who is healthy (not in a terminal state) is to:

- minimize depletion of active muscle tissue in order to optimize oxygen consumption,
- prevent wasting of vital muscle tissue such as pulmonary and skeletal mass,
- promote optimal recovery and minimize functional losses.

As most diseases progress to the end stage, many clients experience weight loss and gastrointestinal disturbances. Caregivers must be sensitive to the fact that food, in and of itself, meets more needs than providing nourishment for a person. Emotionally, food and eating are closely associated with loving, caring, and socializing. In brief, food and eating are about feelings — not just feedings. Unknowingly, health professionals and
family members often use the amount and quality of food as a barometer of the client’s level of wellness or illness. This approach can become a source of conflict and lead to power struggles. On the one hand, family members may report concerns that the client is starving because they are eating very little or “nothing at all.” On the other hand, a client may report that they only eat because of the demands and expectations imposed by family members. When addressing nutritional needs in end of life care, teaching and providing emotional support to the family must be viewed as equally important to maintaining adequate nutritional intake for the client’s comfort.

Preliminary nutritional counseling for a client should be designed to determine basic daily nutritional needs. Subsequently, dietary and fluid intake must be adapted to the limitations imposed by the illness. The health professional must be able to incorporate into the care plan the client’s personal food preferences. Finally, auxiliary and volunteer caregivers must be instructed on how to prepare and serve the diet (food, fluids, supplements) to optimally meet the nutritional needs of the client. Nutritional counseling and recommendations should include the best or most appropriate route for dietary intake based on special circumstances. For example, a gastrostomy tube may be appropriate for a client with esophageal cancer – if the client agrees to this intervention option.

Over the course of the illness and as end of life care continues, most likely there will be a need to modify the consistency, amount, time intervals and route of nutritional intake. Caregivers need to be involved in the client system’s decision making, and with the interdisciplinary team discussions. Likewise, the nurse may need to support and educate other health professionals regarding the implementation of changes in the nutritional care plan, but only if it is ordered by the primary care provider.

**Emotional and Communication Support**

Health professionals providing care to terminally ill clients must be sensitive to the reality that depression, anxiety, and sleep disorders may be present and may cause physical or emotional symptoms. Furthermore, unique psychosocial issues accompany terminal illness. Emotional responses such as denial, anger, sadness, acceptance, and hope may vary from day to day and may differ between the client and the various members of the family.

Coping skills to deal with the loss of the loved one also may be limited, or dysfunctional, in some family systems. Moreover, even family systems that have effective coping abilities may find relationships strained at some time or another during a terminal illness. Finding meaning and purpose in the midst of suffering and loss are spiritual issues a dying person and his or her family must face. (Issues related to grief and bereavement are examined in more detail in a subsequent section of this course.)

Obviouisly, one of the most critical components of end of life care is effective communication between and among the client, caregivers and family members. Caregivers involved must be aware of the opportunity and carefully listen for an opening for communication on the part of the client. Most dying persons want to talk about the process of their own death with loved ones. Often times, family members feel extreme discomfort with the topic, and are unable to participate in discussions of death and dying. In these situations, health professionals can lead the way and assist the family system to “feel that it is okay to talk about death and dying within the family.” Many times the patient may feel that they have worn out the friends and family by discussing this resulting in increased frustration. Volunteers can be a huge help with active listening.

Many times, actually saying the words “death” or “dying” provides an opening for communication to begin on the topic. If the caregiver is comfortable with those words, that in and of itself can help others to feel more comfortable talking about the highly sensitive topics of death, loss and grieving.

In one case Mary, 72 years old, had end stage cardiac disease and was having trouble making a decision about continuing to live at home. Mary wanted to remain at home but her family was very concerned about her living alone. When asked what she believed their real concern to be Mary said, “I think my family is afraid they will come into my home and find me dead.” When asked if she was afraid to die at home or even alone, her response was, “Heavens, no! This is where I want to spend my last days. I want to die where I lived for the last 50 years with my husband and children. My husband died in our house 7 years ago. This is where I belong.”

Often times a patient needs to be told good bye or that it is okay to go. Sometimes the reassurance to the dying father of “we will take care of mother” allows the patient to rest and die in peace.

Her hospice case manager informed Mary, the client in this case, that she has “capacity” to make her own decisions. To help reduce the family’s anxiety, Mary agreed to carry a portable phone with automated dialing for quick access to her family and doctor. This strategy reassured the family, and it allowed Mary to live at home even with the seriousness of her illness. In the end, upon making a routine home visit, Mary’s nurse found her deceased in bed. In essence, the care plan for this woman focused on assisting her to live and die in the manner she desired.

Hospice should be about assisting the family in saying the “I love you’s” and the “please forgive me’s” that have not been said to this point. This often brings resolution and healing to estranged or hurting family members.

**Communicating with Children**

Nurses may find their terminal client to be a child. Caring for a dying child can be a very uncomfortable situation for caregivers, which subsequently is reflected to the client system. This creates more discomfort and limits effective communication among all the players in the scenario. Part of the problem stems from the fact that most of us tend to identify other children’s situations with our own. Most of us believe that children should be healthy and not dying — that is better left to the elderly.

Nonetheless, we must accept the fact that children become ill and children die. Likewise, end of life caregivers are expected to deal with difficult and often painful situations associated with the death and dying of youth. To effectively communicate we first must recognize the child as a person, having his or her
own physical and emotional needs, fears and wishes regarding care. Families having open communication regarding their own or a family member’s death are less likely to experience anxiety, withdrawal and isolation than are those who are protected from this information. Therefore, open communication should be encouraged and facilitated among all members of the client system.

Even young children have the ability and desire to participate in decision making about their care. Conversely, parents often have concerns about what the child understands and how to best address misconceptions and fears. Additionally, if there are other children in the family, parents must try to meet their needs and explain what is happening to their sibling. Support must be given to parents in helping to recognize the unique needs of each of their children. Support may entail making referrals to other team members, or simply listening to parents as they work through their own role issues. Validation by nurses can go a long way to give support to parents during these difficult experiences with their family.

When working with children having terminal conditions, consideration must be given to the developmental level of the child. This is best accomplished by spending time talking to the child about a variety of topics, including their perceptions of the disease, its progression and ultimate prognosis. Each child’s cognitive development progresses at its own rate. Piaget’s conceptualization of the stages of a child’s cognitive development suggests the ways that children at various ages may perceive death. It is important to stress, however, that cognitive development is individual and not necessarily a linear process. Some children develop faster in some areas than in others. Also, in dealing with stress, children can regress to less mature behaviors, such as drinking out of a younger child’s bottle, incontinence and “clinging.” (Figure 6)

Health professionals often remark that many children with terminal conditions seem to have a greater understanding of death than their healthy counterparts. Moreover, most tend to be acutely aware of their medical condition and the effect it is having on other members of the family. Some terminally ill children go to great extremes to protect adults by hiding the extent of their knowledge about their disease progression.

Consequently, when caregivers respond openly, comfortably and in a flexible manner to the child’s questions about his or her condition, it usually helps them to feel more secure and supported. Other communication strategies that caregivers may find effective in dealing with children include:

- Demonstrate an open and comfortable attitude
- Allow the child to set the pace in the conversation
- Respond to questions that are asked by the child (Also make sure of what they are asking, don’t assume a deeper question is present. This is akin to “mommy where did I come from” when parent panics thinking about sex and the child simply wants to know if the stork brought them or did they come home in a car.
- Provide effective pain management to reduce anxiety and increase the child’s comfort level
- Involve the child and the family in

Piaget’s Stages of Cognitive Development

<table>
<thead>
<tr>
<th>Age</th>
<th>Cognitive Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-3</td>
<td>• separation phase&lt;br&gt;• events perceived at feeling and action level&lt;br&gt;• unable to differentiate death from temporary separation or abandonment</td>
</tr>
<tr>
<td>3-6</td>
<td>• structural phase&lt;br&gt;• egocentric&lt;br&gt;• lacks logical cognition&lt;br&gt;• views death as temporary or reversible&lt;br&gt;• magical thinking&lt;br&gt;• may believe they can cause death with their actions or thoughts&lt;br&gt;• envisions death to occur only in the aged</td>
</tr>
<tr>
<td>6-12</td>
<td>• functional phase&lt;br&gt;• concrete mental operations&lt;br&gt;• begins development of logical thought and problem solving&lt;br&gt;• begins to recognize that death is irreversible&lt;br&gt;• interest in specific details of death (decomposition, burials, coffins); begins to perceive death as a reality for them</td>
</tr>
<tr>
<td>12 - adult</td>
<td>• formal operations phase&lt;br&gt;• able to reason abstractly&lt;br&gt;• thoughts about death consistent with those of adults&lt;br&gt;• begins to recognize the effect of death on other people/society</td>
</tr>
</tbody>
</table>

Figure 6
the care

- Be flexible when carrying out procedures (e.g., work with a child’s favorite stuffed animal or doll; allow the child to rehearse or recreate procedures with puppets)
- Use specific and literal explanations (“going to sleep, to heaven, or on a long trip” can be confusing to a child)
- Give the child space and recognize the need to be alone
- Involve other disciplines that allow the child to communicate using creative arts (e.g., music, play, or art therapy)
- Pet therapy has been found useful to create opportunities to communicate with children
- Become aware of other hospice services that specifically focus on the needs and issues of children, and make referrals accordingly.

In brief, providing care to terminally ill children can be a challenge and extremely stressful.

Caregivers must be sensitive to the family-system dynamics as well as the knowledge and developmental level of the child to effectively implement the care plan.

**Touch as an Intervention**

Touch is another core nursing intervention of end of life care, and research supports the comforting power of the human touch. Touch can be reassuring and comforting to the person who is dying and also to members of the family system. When nothing else seems appropriate for a caregiver to do for the client, one can always use touch in a meaningful way. Rarely is it inappropriate to hold the hand of a family member or to stroke the brow of the dying person with a cool damp cloth. Likewise, caregivers should always make an effort to have a bottle of lotion placed near the client. This nonverbal action gives permission and reminds caregivers and family members to rub a shoulder, stroke an arm, or massage the back of the loved one who is nearing the end of life.

Touch is important for caregivers to help make the client comfortable. Remember, the caregiver’s attitude sets the tone and establishes the comfort level for everyone in the environment. However, touch as an intervention in terminal care does not mean that people should hover over the dying person. Rather, if the client is comfortable with this, the family should be told that it is permissible for an individual to read aloud, for children to play nearby, or for the client’s favorite music to be played in the room. It is comforting for others to simply be near the dying person, and touch can become an important dimension in these routine activities. Family members, however, must be encouraged to continue with their usual activities as well, so the terminally ill person does not experience the immediate environment as “strange or frightening.” Dying is, and should be, as natural as any other part of life occurring in one’s usual and comfortable surroundings.

**Financial, Cultural and Legal Considerations**

Individuals in the end of life stages of life and their families face a variety of personal, financial, cultural and legal issues. More specifically, they often experience and must cope with multiple losses along their ultimate life journey. As the disease progresses, the client and the family system find that loss of time from the job(s) results in reduced or no income. Chronic illnesses also place a burden on family finances. Even if the client has insurance coverage, most third-party payers do not cover 100% of the incurred medical costs associated with chronic illnesses and end of life care. Families often must confront extensive medical costs associated with the long-term need for items such as medications, physician services, surgery, diagnostic procedures, hospitalizations, chemotherapy, radiation therapy and nursing services.

In addition to the financial losses, the client system may experience the personal loss of support systems and the inability to perform designated life roles, such as spouse, parent and friend. Actual and anticipated losses all result in grieving in one form or another on the part of the ill and dying person and for loved ones. Isolation and loneliness can occur, and sexual and intimacy issues often are not addressed among family members.

For example, Katherine is a 32-year-old married woman with terminal cervical cancer requiring a colostomy and a gastric tube. The hospice team noted that she had become seriously depressed over the past month. After establishing rapport with her home health nurse, Katherine expressed great sadness about the relationship with her husband. He was able to provide the complicated medical care she required, but had extreme difficulty talking about her impending death. Nor did he meet her need to be touched and feel loved.

Or, for instance, persons infected with the HIV virus may be estranged from family. In some cases, families that actively support a member with AIDS may be isolated from, or sometimes even shunned by their community because of ignorance and the stigma associated with the condition. These kinds of attitudes and lack of knowledge can lead to anxiety, depression and manifestation of a range of physical symptoms, too.

Cultural issues also are important considerations in how the family communicates, interacts and grieves its losses in life. In brief, a person’s cultural beliefs and values define one’s roles, expectations, behaviors, and attitudes toward illness and death. A sick or dying person’s culture is an important factor in whether they will be comforted, isolated, accepted or rejected by their family system and the community.

Legal issues can pose serious concerns for a client and the family system. For instance, upon enrolling in hospice care services, clients are encouraged to initiate a power of attorney, write a will, prepare advanced directives and identify guardians for dependents. Early on, dying clients and their families should be encouraged to confront and resolve these kinds of legal issues. This may involve the nurse providing support to family members as they pursue those responsibilities. Resolution of legal concerns can help to put closure on unresolved life issues; and, ultimately help in the palliative management of symptoms such as anxiety, pain and the physiologic demands of oxygen. Consequently, in some client systems referrals may need to be made for legal consultation to resolve such issues.
Dealing With Losses

An important component of terminal care is meeting the emotional needs of the client’s family system related to experiencing death and loss. This support often includes helping them with the grief and bereavement processes. A family system (and sometimes the client) often experiences what is described as anticipatory grief; grieving or mourning a loss before the event actually occurs.

Theories for Grief and Bereavement

In essence grief is described as the stages (phases) one goes through in the process of accepting a loss. Kuebler-Ross stages of grief are Denial-Anger-Bargaining-Depression-Acceptance. These are not necessarily linear, can be entered into at any point and may be repeated multiple times.

Grief is an intense emotional response often characterized as a deep and violent sorrow. Yet, bereavement is a natural and necessary process that is part of adjusting to a loss. Loss may be the real (or anticipated) separation from a loved one, intense disappointment at not receiving an anticipated reward, failure to experience a normal life-developmental event, or the death of a loved one. Additionally, those who live often experience guilt for surviving (survivor’s guilt) as they struggle to give the death experience of a loved one some type of meaning.

Social theorists have put forth a number of theories of death and dying, and each has its own set of terms to describe the grief process. All, however, indicate that each individual experiences grief differently, and that the stages involved are not necessarily sequential in nature. It is an emotional progression and regression in the healing process. Everyone grieves in their own way, with emotional progression and regression in the healing process influenced by major life events as well as by day-to-day activities. If a loss remains unresolved, the grief process becomes prolonged to the point of dysfunction in the client system.

Some theorists list specific phases for grieving. However, discrete stages can be difficult to differentiate and the process generally is not experienced in a textbook manner by the bereaved. A few people never fully adjust to a loss, and consequently can remain emotionally fixed in one particular phase of the process. With the admonition that it is not linear and that each person experiences grief differently, the ensuing discussion elaborates on the bereavement process.

(Figure 7)

The Grief Response

The first response to a loss or crisis is shock and numbness. Initially, the person denies the loss, expresses shock and may withdraw from routine social situations. Other behaviors often exhibited are short attention span; difficulty concentrating; disorientation to time and the actual sequence of events; impaired decision-making ability; resistance to new experiences; stunned disbelief; and failure to accept reality. This preliminary phase may last only a few hours, or several weeks or months. In some cases, the preliminary phase can last for years.

This preliminary response to loss is followed by a searching and yearning phase. During this time the person experiences rage at those who inflicted the pain, at society for allowing the events to occur, and sometimes at oneself for being part of the event (even if given no choice about one’s role).

This is followed by a phase characterized by increasing resentment; guilt; restlessness; impatience; depression; giving double meanings to recent life events; dreaming about the event; bitterness; testing reality; emotional instability; difficulty sleeping; preoccupation with the loss; and complaints of physical discomforts, e.g., headaches, gastrointestinal distress, back pain, heart palpitations, frequent sighing, and lethargy. Each person uses different coping strategies to reduce the discomfort, some of which may be more healthful than others. Commonly used coping strategies include immersing oneself in work, meditating, exercising, talking about the experience, isolating and using medication. Less healthful coping strategies include the use of mind-altering chemicals or alcohol, overeating, or abusing another person or animal. This third phase also varies in length of time from individual to individual, and from situation to situation.

Finally, there is the reorganization and resolution phase of the bereavement process, when the anger, sadness and mourning decrease in frequency and intensity. The individual accepts the reality of the loss and incorporates the event into their belief system. The person experiences a sense of relief and renewed energy, resumes routine eating and sleeping habits, makes better decisions with greater ease, improves his or her self-perception, finds reasons to smile, and plans for the future.

Dysfunctional Grieving Patterns

Health professionals providing terminal care should be aware of and acknowledge that the client system must be allowed and encouraged to grieve for healthy adjustment to occur. Bereavement can become stressful for the person, and others in the immediate environment, especially when grieving continues for an extended time. Behav-
ors associated with prolonged grief include chronic sorrow, anger, loneliness, sadness, shame, anxiety and guilt. The appropriate time frame for grieving to be completed is not delineated, and cultural factors play a significant role in the process. Some propose that the longer one grieves for a particular loss the more likely this behavior is to continue. Others propose that denying the loss, or failing to completely work through the grief process, can be detrimental to the long-term health of a person’s body and mind. There is no one reason for the development of dysfunctional grief patterns. Prolonged grief often is associated with certain diseases, especially cancer and other chronic health problems. Dysfunctional grieving can also be an outcome of the following situations:

- Actual or perceived loss of an object or self, as seen before the traumatic incident occurred (e.g., limb, reproductive organs). The sensation can be exacerbated by other losses that occur during or after the event.
- Loss of physical, psychological or social well-being.
- Thwarted grief response or lack of resolution of previous loss(es).
- Absence of anticipatory grieving. That is to say, the lack of personal awareness of something going wrong or an impending loss.
- Guilt feelings for surviving when others, particularly peers, did not (survivor’s guilt).
- Families with unrealistic or unreasonable expectations of the hospice team.

Supportive bereavement services usually include education and counseling provided to the grieving family for up to 24 months following the client’s death. Support groups should be recommended for both children and adults. Likewise, telephone contacts with others having similar experiences with loss, personal visits with peers, individual counseling, and provision of educational materials are strategies that can help provide insight to the grieving family system.

**Healing the Healer**

Ever since the hospice movement started in this country during the mid-1970s, there has been concern that burnout among caregivers would negatively affect the quality of services that are delivered to their clients. This observation also applies to caregivers providing care to a client in the terminal stages of life. Job stress and burnout have been cited in the nursing literature as major causes of job turnover, poor job performance and abuses of the client (Figure 8).

Burnout is a term that has been used in the literature to describe a syndrome that involves prolonged contact with clients, with inadequate concern being given to the caregiver’s physical and emotional needs. It has also been referred to as low level depression. Eventually, the cyclical pattern leads to emotional exhaustion, a decreased sense of personal accomplishment, and increased depersonalization of the client by the caregiver.

**Identify the Source of Stress**

To implement stress-reduction measures for caregivers, it is important to understand the nature of the stressors and an individual’s perception of the measures used to handle them. Research supports the belief that caregivers, nurses in particular, who work with terminally ill clients experience high levels of stress. A major stress for hospice nurses stems from organizational issues, however, rather than from client care issues. Organizational stress is related to administrative issues and is different from client care burnout. The distinction between the two sources is an important consideration when planning a stress management or stress reduction program. Likewise, the intervening actions will differ for each precipitating source. More specifically, a group of hospice nurses described the most stressful organizational/administrative factors in their practice to be:

- physicians who do not understand hospice care,
- too many clients dying at the same time, and
- the large amount of paperwork expected of them.

The least stressful factors were stated to be:

- poor communication with administration,
- the number of clients seen per day,
- poor nursing staff interpersonal relations,
- poor communication with the interdisciplinary team,
- the general hospice environment, and
- participation in research studies.

As far as patient care burnout, hospice nurses find the most stressful client diagnoses to be chronic obstructive pulmonary disease, and bone, lung, pancreatic, and brain cancer. The most difficult aspects of client and family management were listed as pain control and managing physical symptoms. The elements nurses find least difficult in their practice are providing emotional support to the client system and coordinating community resources. Administrators should consider these stressors when planning and evaluating nurses’ workloads with terminally ill client systems.

**Stress Management Strategies**

In addition to determining the sources of stress, be they administrative/organizational or client-related, the following measures can be useful in reducing stress. Most important, of course, is participating in healthy self-care practices, including good nutrition, daily exercise, adequate rest, relaxation, and meeting spiritual needs. Other effective stress-reducing methods are discussing work-related concerns with someone affiliated with a hospice, working part-time, taking time off, and humor. Discussing concerns with non-agency/hospice personnel and meditation generally are less helpful to hospice nurses in managing work-related stressors.

As for the adequacy of support systems for nurses in hospice agencies, the most effective is reported to be with peers and co-workers. A few find formal support systems more helpful such as a professional counselor or social worker. Generally, caregivers do not find discussions with family and friends about work-related issues to be a valuable stress management strategy. Unfortunately, the majority of employees do not find the support offered by their employers to be adequate. Hospice nurses concur that more needs to be done to address employee concerns that can lead to professional burnout.

Administrators might consider offering more flexible scheduling as a way to reduce and manage stress in those offering care to the dying. For instance,
Risk Factors for Abuse Of Terminal Client

- Prolonged illness without respite for caregiver
- Isolation (e.g., geographic, social, emotional)
- Stressful events (e.g., financial hardship, loss [job, loved one])
- Substance abuse
- Lack of financial resources and support services
- Cognitive impairment
- History of mental illness
- History of domestic abuse/family violence
- Shared living arrangements

Figure 8

Working part-time, taking time off, and flex scheduling among two or more nurses can allow reprieve and personal renewal. The high number of client visits scheduled each day is cited by some as a significant source of stress. Interestingly, though, some hospice nurses with higher client-to-staff ratios do not experience burnout as readily as counterparts in hospital settings. Many report that working with client systems in the home is one of their greatest sources of job satisfaction. It is not surprising that excessive paperwork repeatedly is identified as a major stressor in hospice nurses’ lives. Paperwork, although important, prevents caregivers from spending time at the bedside with the client. Every effort should be made by the sponsoring agency of end of life care services to streamline the paperwork requirements within the organization in order to maximize the time a caregiver is able to spend with a client system. However, external regulatory agencies (state health departments and federal agencies for MEDICARE) have a multitude of mandates that require careful documentation for legal, financial, and policy purposes.

Communication, or the lack thereof, with administration, the interdisciplinary team, and fellow caregivers is also a source of organizational stress. To address this concern, every effort should be made to teach conflict resolution and assertiveness skills to all employees. Other factors that contribute to job satisfaction and reduce the stress level of caregivers include professional autonomy and independence. For instance, some nurses prefer working independently while others prefer an environment where they can interact more spontaneously with co-workers. Hospice administrators should be sensitive to those individual preferences when making assignments. Employees, too, must remember that effective communication is a two-way street; therefore, they should learn to express effectively their preferences and needs to supervisors.

Some question whether community and home care agencies allow for spontaneous or more accessible peer interactions. Opportunities do exist in these settings; however, distances between providers may be greater in community-based agencies than for a team of staff members located on a hospital unit. Providing end of life care for clients whose management of pain and other symptoms is out of control contributes significantly to caregivers’ frustration with physicians who do not understand the philosophy of the hospice model. Medical schools in the United States traditionally have placed only a limited amount of emphasis on physicians’ relationships with terminally ill client systems. Physicians, as a whole, do not fare well when it comes to supporting clients by making home visits, communicating with families, and revising their treatment approach from curative to palliative care. This knowledge deficit reinforces the need to educate medical as well as nursing students on the hospice philosophy of allowing a person to die with dignity.

As for the emotional needs of caregivers, employee programs should be in place to offer support in the form of counseling as well as in-service classes on death, dying, symptom management, use of new technology, assertiveness training, problem solving and communication skills. Professional Boundaries is also a topic that needs to be taught/reinforced.

Likewise, information on health promotion, exercise, recreation, and humor as stress reducers could be included in employee support programs. These strategies can go a long way to prevent caregiver stress and burnout from occurring. Religious and spiritual practices are useful, too, in helping to manage stressful life events. During all the discussions, participants should be encouraged to express their feelings about death and dying and have access to a chaplain. In brief, it is essential for agencies offering terminal care to offer stress-management programs to employees, so they in turn can provide quality care for their client systems.

Values Clarification About Death and Dying

In order to provide meaningful and effective terminal care to the dying person, health professionals must first reflect on their own vulnerability and on death itself. The following items are examples of questions that should be considered in a self-appraisal.
Reflect on Personal Experiences

Who was the first person that you recall dying? Most of us were too young to assist in caring for the first dying person in our life. However, memories remain and this influences one’s perceptions about death and the dying process.

* After the person died, how did the family grieve?
* How was that particular death integrated into the family’s history?
* Describe the first death you can recall; the first funeral you attended. What frightened you about that event?
* What questions do you still have about that death?
* Whose is the most recent death you have experienced? The most traumatic death you were involved in?
* Describe the situation in which you came closest to dying.
* What is your greatest fear about dying?
* Have you ever had a near death experience? If so, describe it.

For example, a caregiver on a hospice team recalled, as a young child, seeing his beloved grandmother die in the family home. Now, all of the people he cares for in his practice remind him of his Grandma. He describes his feelings in these words:

“I am comfortable with my clients when they require end of life care. They need me to help them get through that stage of life. I find that most want to be kept clean and comfortable. Some are embarrassed for family members to provide that kind of intimate and personal care for them. I am able to do that for them, all the while teaching family members how to provide personal care for the loved one. In one case a woman who was nearly comatose, so as to not burden her family, crawled out of bed to take a shower. Upon my arrival in the home we found her lying on the bathroom floor. We helped her get back into bed. Then, I encouraged the family to sit with her, rub lotion on her legs and arms, and to talk with her. Six hours later she took her last breaths. Being clean was so important to this woman.”

This particular caregiver’s comments reinforce that routine activities of daily living really are the important tasks of terminal care: completing routines that help a client and family feel comfortable with themselves and each other.

Confront Your Own Mortality

Experts on comforting the bereaved and caring for the dying frequently emphasize the need for health professionals to confront their own mortality. Caregivers must be grounded in their own beliefs, yet willing to accept the beliefs of the client system even though they may be different from one’s own. This sounds great in theory, but few caregivers know how to achieve such a state of mind. Values clarification strategies can help to confront one’s own death, freeing one to give comfort to others.

Raise Awareness

* How aware are you of your own death?
* Have you thought about your limited lifespan?
* Have you experienced a fear of death?

Interestingly, a normal adult thinks about death an average of one to three times each day. However, days may pass without a thought of death. Then, depending on what happens in our life, one may incessantly ponder mortality on other days. Being aware of one’s vulnerabilities helps to give some degree of control over our responses to it.

Pick a Life Span

How old do you think you will be when you die? On the timeline (Figure 9), place a slash mark to represent where you are on that timeline today.

Now roughly calculate in years how long you expect to live (chronological age). Indicate with slash marks, your lifetime from birth to your projected death.

Compare your timeline projection with your chronological (numerical) age estimate. Are you comfortable when estimating your life span? Why or why not? Select your preferred style of death. Describe it briefly. Why do you prefer this? Describe your least preferred way of dying.

Each of us has a unique lifestyle, and most people die in a way that is similar to how they lived. For example, a daredevil may die as a result of recklessness. A sedentary person may become bedridden. Others who are dedicated to a particular vocation or mission in life often die while engaged in that activity, e.g., a researcher on yellow fever dies of that illness; a singer dies of throat cancer.

Is there a way to prevent the death you would least like to have? What are your preferences when it comes to your death?

Write Your Obituary

Write down what you would like to have said about you after you die. Upon reflection, do you find anything you need to change in your current lifestyle? Do you need to make new plans, or set new goals to accomplish what you want said about you after your death? Are there projects you need to start or finish? If the answer is yes to any of these, how can you develop an action plan to achieve those outcomes?

Life Time Line

<table>
<thead>
<tr>
<th>Your birth date</th>
<th>Current place in life</th>
<th>Projected time of death</th>
</tr>
</thead>
</table>

Figure 9
Prepare for Your Own Death

To reduce anxieties about your own death, make a written plan that outlines your finances, belongings, and what you would like to give others.

Be specific about whether or not you desire the use of extraordinary measures to prolong your life; what to do with your body; whether or not to have a funeral; and the role you would like organized religion to play in your funeral or memorial service. Carefully consider the following options and how these can impact your own death.

Life Insurance

Could your family continue at the same living standard for three to five years without your presence?

Do you have special needs that must be considered, such as a disabled spouse, several young children or a physically challenged child?

Remember, an accountant or financial advisor can be invaluable when considering your life insurance needs.

Last Will and Testament

Contrary to popular superstitions, making a will does not cause anyone to die sooner. There literally are dozens of good reasons for having a will and the list below includes some of them:

- Choosing your executor
- Deciding on the inheritance of your property
- Appointing personal and property guardians for minor children without expensive legal proceedings
- Saving money on taxes and inheritance fees
- Providing loved ones with information about your concerns and specific intentions. It is advisable to have an attorney set up your will in order to eliminate the possibility of legal errors that could be costly to your survivors.
- Preparing Advanced Directives that may include a Living Will and Durable Power of Attorney for health care decision-making if you are unable to do so.

The Role of Advance Directives

In recent years, it has been increasingly recognized that an individual has the right to self-determination not only with regard to activities during life, but also in choosing services that will enhance the quality of life during her final days. The person may have chosen an executor, made decisions regarding disposition of personal property, and provided loved ones with information about specific concerns and intentions. An important part of this process is the preparation of advanced directives that may include a living will and a durable power of attorney for health care decision-making in the event of incapacitation. If the person decides that he does not want to be maintained by gastric feeding or mechanical ventilation, then those decisions can be conveyed to the physicians and others involved in his care.

Many individuals at the end of life have reported considerable comfort in knowing that they have expressed their wishes and are to be allowed a death with dignity according to those wishes. Healthcare professionals can assist their patients to achieve this level of peace by encouraging the preparation of advance directives.

Nurses are committed to providing care to the whole person throughout the life span, and to maintaining a holistic perspective on the needs of the person in their care. What could be more important than gathering all the nurse’s personal strengths and professional skills to provide caring support to those facing one of life’s greatest transitions?

Many people, especially health professionals, say they do not want to be brain-dead, tube-fed, or turned and wiped every two hours until antibiotic-resistant pneumonia intervenes. To avoid this horror, express your wishes in advance directives, such as a Living Will (if recognized in your state) or a Durable Power of Attorney for Health care. The latter allows you to appoint another person to make your healthcare decisions for you, subject to whatever limits you wish, should you be unable to make or express your choices. Preferences for organ or tissue donation often are included as part of a Living Will. If this is your desire, it is prudent to carry a signed organ donor card in your wallet. In some states, this preference is stated on driver’s license cards.

It should be pointed out that some States have taken to calling a “no code” a “Do not resuscitate order” which has a negative connotation and may make the family feel that they are failing the person by not advocating for their resuscitation. Whereas other States refer to it as “Allowing Natural Death (AND)” which implies that death is a normal process and not to be feared and that not intervening is okay.

Make Funeral Plans

Funeral plans made and stated prior to death allow for the family to make wise financial decision instead of spending out of grief or trying to make up for lack of care prior to death by spending money after the death. Therefore, if the funeral plans are established documented by the dying one, the family is spared additional grief.

Also, doing this prior to the death, can allow the family to move forward in some of their grieving. The following are suggestions to help with these plans.

After you die, how do you want your remains handled?

- What type of service do you want?
- Where do you want the service held?
- What do you want included in a service?
- Who would you like to participate in your memorial service? Remember, it may be too difficult for your family to speak, sing or play a musical instrument, so it is best to name friends to carry out those activities.
- Are there songs or other special music, statements, poetry, readings, Scriptures or other materials you would like included?
- Are there things you want excluded from your memorial service?
- Where do you prefer to be buried?

Only by confronting our own vulnerability are we, as caregivers, able to provide sensitive, appropriate and acceptable care to our terminally ill client systems.

Key Points in Palliative Care

The most recent information released
by The Institute for Clinical Systems Improvement (ICSI) includes guidelines for treatment of palliative care issues. Major recommendations include clinical highlights and key points for healthcare professionals including:

- Palliative care planning should begin early in the patient’s journey of a progressive, debilitating illness. A key question for providers is “would you be surprised if the patient died within two years?”
- Where palliative care consultation is available, referral to this service should be done early on in the patient’s care.
- Where palliative care services are not available, primary care providers should begin palliative care planning early.
- Health care providers should initiate palliative care conversations with their patients.
- Health care providers should complete a systematic review and document patients’ goals for care and advance directives.
- Pain and physical suffering are common in this patient population, but there are nonphysical areas of suffering that also need to be addressed. These include cultural, psychological, social, spiritual, religious, existential, ethical and legal issues.
- The ability to address these issues depends, at least partially, on the quality of communication with patients and families. Setting realistic goals of care and providing realistic hope is essential.
- In the delivery of palliative care, aggressive interventions may continue with an increased focus on symptom management.
- Health care providers play an important role in the grief and bereavement processes.
- General considerations clinicians should use to identify patients who would benefit from palliative care planning include:
  - Disease progression, especially with functional decline
  - Pain and/or other symptoms not responding to optimal medical treatment
  - Need for advance care planning

Guideline met for hospice eligibility, but “not ready”

Conditions that may prompt palliative care planning include debility/failure to thrive, cancer, heart disease, pulmonary disease, dementia, liver disease, renal disease, neurologic disease such as stroke, Parkinson’s, amyotrophic lateral sclerosis (ALS), multiple sclerosis (MS). For more information on these conditions refer to the original guideline document.

Many residents in long-term care facilities have these conditions and should be assessed for palliative care.

**Initiate Palliative Care Discussion**

The ability to frankly discuss and plan with patients and families is as important as any other medical interventions. Practice and experience with discussions about end-of-life decisions and palliative care will improve providers’ skill and comfort levels.

Many providers feel they lack confidence and experience in discussing with patients the issues and decisions that come with having a progressive, debilitating illness – specifically recommendations about palliative care and hospice services.

There are several excellent mnemonics available to help providers increase their knowledge, practice examples of these discussions, and generally obtain a better understanding of the emotions, questions and problems that may arise with patients and families at this time in their lives.

The mnemonic below can be used to help prompt a successful conversation with patients and families:

**ABCDE** (Advance preparation, Build a therapeutic environment/relationship, Communicate well, Deal with patient and family reactions, Encourage and validate emotions)

**Advance preparation:** Obtain the patient’s medical information and test results, if possible, so that you are fully aware of the situation. Mentally rehearsing the way you wish to present the information and options can give you a sense of how the conversation may go. Remember to individualize your approach for each given patient based on how much they know at that point and how they prefer to receive information. Make sure that you have an appropriately private location in which to have the discussion.

**Build a therapeutic environment/relationship:** Try to find out how much the patient and family understands, how they want to be told (bluntly, gently, etc.), and how much they want to know at that time.

* “If this condition turns out to be something serious, are you the kind of person who likes to know what is going on?”
* “Would you like me to tell you the full details of the diagnosis?”
* “If your condition is serious, how much would you like to know?”

If the patient indicates that he/she does not want any information, it is important to “leave the door open.” For example you may say, “That’s OK. If you change your mind, at any time, please feel free to talk to me or one of my colleagues.”

Have family members or friends present as per the patient’s preference, and take time to learn names and relationships of each support person present. Use touch and humor where appropriate, taking into consideration your relationship with the patient. Reassure the patient of your availability, set up follow-up appointments, and contact other providers about the situation where appropriate.

**Communicate well:** Ask the patient for any questions. Speak truthfully but compassionately and avoid using medical terms or euphemisms. Say the words cancer, dying, death, etc. Don’t rush the process; allow time for silence, tears and questions. Remember that the patient may not retain much of the information given past that of the diagnosis or prognosis. Repeat important points and write things down. Think out loud; help the patient and family feel they are part of the team.

**Deal with patient and family reactions:** Be sensitive to the emotional reactions of the patient and family. Recognize that denial, blame, intellectualization, disbelief, and acceptance may be present to varying degrees and time frames. Watch for signs of depression and suicidality in subsequent visits. Be empathetic. Crying may occur but make sure that your tears are empathic.
in nature and not reflective of personal issues on your part. There may be anger from the patient and family about care received from you or another colleague; resist becoming defensive or argumentative about these issues. Try to deal with that particular patient’s and family’s cultural and ethnic norms.

* “I was probably raised differently than you. Can you tell me how your family deals with these situations?”

**Encourage and validate emotions:** Offer realistic hope. This may not involve cure, but can encourage symptom control, dignity and peace at the time of illness/death. Discuss treatment options and arrange for follow-up to put those options into action. Talk with the patient about what this means for him/her, and what needs outside of the traditional medical scope he/she may have.

* “I know this is not what you wanted to hear.”

* Don’t say, “There is nothing more we can do;” instead say, “What are we going to focus on now is (comfort, pain relief, etc.).”

Patient and family reactions to serious illness and decisions about end-of-life care are influenced by numerous factors. For more information this Guideline can be accessed on the National Guideline Clearinghouse website, key search Palliative Care.

**Hospice Resources**

As discussed earlier in the course, hospices often are not-for-profit organizations that attempt to provide services that ensure a quality of life, and dignity in death for terminally ill clients and their loved ones. Interdisciplinary teams of registered nurses, home health aides, social workers, counselors, clergy and volunteers work with the client’s physician to provide holistic support; therefore, a range of services are included to achieve that outcome. For specific information about local services, contact a Hospice agency in your community.

**Bereavement Services**

Bereavement services, offered by home health agencies, hospice programs, hospitals, and mortuaries provide individual and group therapy to help loved ones of terminally ill clients. It can be reassuring for loved ones to know that they are experiencing normal grief reactions and are not alone in the process. Hospice counselors usually are available around the clock and work privately with families and individuals who are having difficulty coping with their loss. People grieve in their own unique way. Hospice bereavement counselors and support groups are available to help individuals and families cope with the overwhelming symptoms. Appointments can be scheduled with a bereavement counselor by calling a nearby Hospice office.

Many Hospices offer children’s bereavement services and group activities, such as annual camps and weekend retreats, for young people ages 6 to 16 who recently have lost a loved one. The combined recreational and peer-sharing activities help create a bond among participants experiencing similar emotions. A special memorial service sometimes is held at the end of the session to remember loved ones in a meaningful ritual.

Support groups for bereaved children are offered throughout the year. These programs are designed to provide a safe and caring environment through creative arts and peer sharing activities. Preferably, groups should be directed by specialized master’s degree prepared counselors or social workers. School counselors should be made aware of these services so they can refer children who may benefit from this type of support.

Adult bereavement support groups are available in many communities across the country. As with children, these should be led by master’s prepared counselors who are skilled in bereavement interventions. By offering mutual support and friendship in small and informal groups, participants realize they are not alone and can begin to adjust to their new lifestyle with peer support. Generally, these sessions are open to the public and held at various locations in a community. Groups should be limited to no more than 10 participants so that every participant has an opportunity to share their experiences.

Another kind of dynamic bereavement group is one that is led by volunteers and offered on a regular basis. The format for this program is educational in nature. The topics address practical issues such as stress management, nutrition and budgeting. Participants are provided with information about community activities and services, as well as having an opportunity to socialize with others who are experiencing similar circumstances.

**Memorial Services**

Memorial services are held regularly to honor and remember hospice clients who have died in recent months. Family and friends of those being honored are invited to attend and share their experiences and memories. Services are non-denominational, designed to meet the needs of people of all faiths and philosophies. For more information about these services call a Hospice office near you or contact a priest, minister or rabbi in your community.

**Speaker’s Bureau**

Hospice organizations often have a speaker’s bureau, and these representatives are available to provide a variety of presentations to community groups, including short educational videos that present an overview of services. Another service of the bureau is community bereavement education. For instance, does the family of the dying person belong to a church, club, or community organization whose members might benefit from bereavement services? If so, a bereavement counselor from the speaker’s bureau can make presentations on available services for the terminally ill or talk on special issues surrounding death and dying. To schedule a speaker, call a nearby hospice, home health agency or hospital for more information.

**Referrals**

Generally in communities having a hospice, family members, friends, health professionals or a prospective client may call to request information about services. In turn, each client is individually assessed to determine the appropriateness of hospice care. Skilled interdisciplinary teams combine their expertise to develop individualized care plans to control pain and manage symptoms. Team members also work with the client and family members to address their psychological, social, physiological, financial, and spiritual preferences. The plan of care, designed by the client system, attending physician and interdisciplinary team members, may include some or all of the following services:
• visits by registered nurses, social workers, counselors, and home health aides as often as needed
• on-call nursing and counseling services, 24 hours a day, seven days a week
• 24-hour continuous care when medically necessary
• training in the care of the client at home
• education about the illness; what to expect as it progresses; ways to cope with limitations and symptoms
• procurement of durable medical equipment, supplies and medication to better manage the terminal condition
• short-term in-patient care for symptom control and family respite
• volunteer support
• spiritual counseling individual and/or family counseling
• bereavement support for loved ones for a year or longer following the loss

Some organizations have an inpatient Hospice Care Center, or a residential care facility. This unique facility provides a warm, home-like environment for a terminally ill client who does not have a caregiver, who no longer is able to remain at home, and is not able to live in another facility.

Volunteer Services

Volunteers fill a number of different roles. All bring unique combinations of skills, interests, experiences and talents to a hospice program. Volunteers generally are required to complete about 16 hours of orientation. Medicare requires hospices to have 5% of their hours provided by volunteers. Ongoing in-service and special educational programs usually are offered monthly. Their responsibilities may include:

Client and Family Care:

Listen and provide emotional support, run errands, read to clients, provide transportation, prepare simple meals, help write letters, perform simple household tasks, and relieve the caregiver for short periods (respite services).

Bereavement Support:

Assist families during initial grief period, provide emotional comfort with telephone calls and personal visits, facilitate support groups, and participate in children’s bereavement programs.

Office Support (in organized/formal hospice programs):

Help with typing, filing, mailings, assist in medical records department, and enter data into computers

Public Relations:

Participate in speaker’s bureaus, assist with fund-raising, make deliveries to celebrate holidays and other special events, assist with children’s bereavement programs such as “Caring Clowns” to visit young clients at home or in the hospital.

Teen Volunteers:

Are matched with their unique abilities to hospice clients’ interests and needs. Assist with office duties, light housework, nursing home visits, children’s bereavement programs.

Resources

Hospice Association of America
202-546-4759
www.nahc.org/HAA/home.html

Services: Largest lobbying group representing more than 2,000 hospices and thousands of caregivers and volunteers who serve terminally ill patients and their families.

National Association for Home Care and Hospice Care (NAHC)
202-547-7424
www.nahc.org


Services: Provides a state-by-state database of phone numbers for state home care and hospice agencies.

National Hospice and Palliative Care Organization (NHPCO)
800-658-8898 (Hospice Helpline) or 703-837-1500
www.nhpco.org

Services: Provides information about hospice programs in your area; also publishes information for consumers and has frequently asked questions on its Web site.

Suggested Readings


Sibbald GR, Krasner DL, Lutz J, “Tip the SCALE toward quality end-of-life skin care.” Nurs Manage, Mar 2011, 42(3) p24-32


Ruder S., “7 tools to assist hospice and home care clinicians in pain management at end of life.” Home Healthc Nurse Sep 2010, 28(8) p458-68
