ISSUES IN PALLIATIVE CARE
COMMUNICATION, TRANSITION, AND END-OF-LIFE MEDICAL CARE
(7 CONTACT HOURS)

Learning objectives
Upon completion of this course, the reader will be able to:
- Identify the primary goals of palliative care.
- Explain the role of effective communication in palliative care and provide an example.
- List and distinguish between medical and psychosocial elements of advance care planning.
- List some of the most important considerations in a discussion of palliative care; explain the significance of location, timing, people to include and possible repercussions.
- Name the members of the interdisciplinary team involved in palliative care and identify the primary responsibilities of each.
- Define palliative care and explain the meaning of “hospice.”
- List some of the issues in a comprehensive assessment for home care.
- List alternatives to home care and describe the resources associated with each.
- Explain the principle of deliberation, the rule of double effect, and the principle of proportionality, and the significance of each in relation to palliative ethics.

Strategies and goals of palliative care [74]
Palliative medicine seeks to provide the best quality of life for patients and families using a model in which the goals of care are collaboratively developed with care providers according to the wishes of patients and families. This model emphasizes communication, collaboration and the willingness to accept patient-focused outcomes as paramount and to respect patients’ wishes regarding such important issues as quality of life or cessation of therapy. The following statements summarize some of the key aspects of the philosophy of palliative medicine:
- Core elements of palliative care: [68]
  - Emphasizes comprehensive care of the whole patient, inclusive of medical, psychosocial and spiritual concerns.
  - Depends on effective communication and relationship building within a model of diverse expertise and interdisciplinary teamwork, not an authoritative hierarchy.
  - Goals of care include relief of suffering, control of symptoms and restoration of functional capacity.
  - Supports neither the goal of cure nor the hastening or prolonging of death.
  - Considers patients’ subjective experience (e.g., pain, other symptoms) to be as important as objective clinical data.
  - Diagnosis is not a predetermined goal; it is only pursued if it conforms to patient-determined goals of care.
  - Death is not equated with defeat but rather is seen as natural conclusion of life; response of the health care worker should be to comfort, not withdraw.
  - Management plan is tailored specifically to each patient, according to patient’s values and preferences, not decided unilaterally by a physician.

This palliative philosophy comes from a model of care that is distinctly different from the familiar, hierarchical and physician-dominated model that characterizes much of contemporary medical care, especially for diseases that have potentially effective therapies. Focusing on the patient and family-centered goals of care ensures that decisions will be made that do not violate important concerns of the patient and family. Curative, palliative, or both types of interventions can be offered, not unilaterally and driven by diagnostic or treatment algorithms but rather collaboratively and driven by the priorities and values of the patient and family.

All scenarios above involve decisions that need to be informed both by medical evidence and risk-benefit analysis as well as by the priorities, values and preferences of patients and families. In all these scenarios, it should be clear that decisions must be based on the specific goals of care, including such factors as:
- The relative values of quality of life or prolongation of life.
- The use of aggressive palliative care interventions to help mitigate side effects of specific medications.
- The use of certain disease-specific therapies primarily for palliative or quality-of-life intent.
- The decision not to prolong life “no matter what,” once a certain important threshold had been reached (e.g., progressive dementia or the inability to manage oral feedings or medications)

Advance care planning
The focus on goals of care incorporates the concept of advance care planning, which includes both medical and psychosocial elements. Medical aspects may include:
- Decision-making about the risks and benefits of specific therapies (e.g., anti-retroviral therapy, chemotherapeutic regimens, etc.).
- The importance of quality-of-life elements in these decisions (e.g., the choice of a potentially toxic, time-intensive intervention that might prolong life versus more palliative measures that would improve short-term quality of life but not extend it).
- Decisions about particular medical interventions (e.g., cardiopulmonary resuscitation, artificial nutrition or hydration, rehospitalization of a patient being cared for at home).

Psychosocial issues that need to be addressed may include:
- Family ambivalence or conflict about care plan decisions.
- Guilt or other emotional “unfinished business” that may affect decisions regarding care planning.
- Concerns that any limitation on curative treatment interventions may represent abandonment of the patient or lack of commitment or concern on the part of the care provider.

Discussions about advance care planning should be ongoing, anticipatory, and re-visited on multiple occasions as needed over time. These issues should be normalized as much as possible and incorporated into routine care, rather than waiting until a crisis, such as an acute life-threatening illness or the loss of decisional capacity, to begin to address them.

It may, in fact, be an indication of the discomfort that providers feel within the either-or framework of curative versus palliative care that they may unconsciously defer these discussions until the patient is precipitously dying, implying that discussing goals of care and end-of-life decision making is somehow inappropriate within the current therapeutic model. However, the approach to these issues needs to be positive, respectful and focused on the values, concerns, cultural beliefs and care preferences of the patient and family. The family and/or other involved individuals need to be included earlier rather than later in these discussions, and decisions about health care proxies and other surrogate decision-makers need to be made clearly and communicated to the designated individuals.

The role of the health care team in communication about palliative care [77]
The health care team is made up of a number of health care professionals, including physicians, nurses, social workers and others. Different team members may play varying roles in different
settings. It is important that all team members who are directly involved in communication with patients and their significant others be aware of all communication about end-of-life care. Consensus within the team is an important step in the process of making decisions about withholding or withdrawing life-sustaining therapy regardless of whether the setting is an intensive care unit, hospital ward or outpatient setting. Of the few legal cases brought against health care providers for end-of-life decisions, most have been initiated by disgruntled colleagues. In addition, it is important that all team members are informed about the medical situation and plan of therapy so that patients and their significant others do not receive conflicting messages from different staff members.

Acute care nurses play a pivotal role in health care worker-significant other communication in the acute care settings. Significant others rate the nurses’ skill at this communication as one of the most important clinical skills of nurses. In a meta-analysis of studies assessing the needs of significant others who have a loved one in intensive care, 8 of the 10 needs identified relate to communication with health care workers, and the majority of these communication needs are primarily addressed by the nurses. In the outpatient setting, nurses, nurse practitioners and physicians’ assistants also may play an important role. However, there are data to suggest that nurses are not better at communication about end-of-life care than physicians and, in fact, in the outpatient setting, nurse practitioners and physicians’ assistants may actually not do as well as physicians in communication about the end of life. Consequently, it is likely that nurses, nurse practitioners and physicians’ assistants could also benefit from efforts to improve the quality of this communication.

In acute care settings, social workers often play an important role in identifying and contacting significant others, coordinating and scheduling family conferences, and keeping in contact with significant others during the hospital stay. This is a very important role in providing sensitive care and in communicating with patients’ significant others. The person filling this role should be aware of the medical prognosis and plans and be an active part of the health care team. In the outpatient setting, social workers may be the ones primarily responsible for many of these discussions with patients and consequently need to develop the same skills and expertise in this communication.

The role of culture and ethnicity in communication about palliative care
Culture and ethnicity are important factors to consider in patient-health care worker communication, and cross-cultural dynamics may be especially important in discussing palliative care for patients. It will be important to identify the barriers to communication unique to these patient groups and individuals. Health care workers should be aware of the diversity of barriers that may exist for patients from different cultures and be open to discussing these barriers openly with patients.

When to talk about palliative care
It is impossible to be prescriptive about the right time to discuss palliative and end-of-life care, except to say that we should talk about it earlier than we usually do. Often, health care workers, particularly physicians, wait until they have decided that life-sustaining treatments are no longer indicated before they initiate communication about palliative and end-of-life care with patients or their significant others. Patients and significant others may be just beginning to think about withdrawing life-sustaining treatments while health care workers are feeling increasingly frustrated at providing care they believe is no longer indicated. Alternatively, the patients and significant others may be considering withdrawal of life-sustaining treatments well before the health care team. The team members may also vary in the timing with which they believe that life-sustaining therapy should be withheld or withdrawn. In the acute care setting, nurses often come to this conclusion earlier than physicians, which can lead to extreme frustration for some nurses and interdisciplinary conflict for physicians and nurses.

A potential solution to this difficulty is to begin discussions with the health care team, patients and significant others early in the course of a chronic illness. However, early in the course of care, these discussions may focus on prognosis, goals of therapy and the patients’ values and attitudes toward medical therapy. These early discussions may foreshadow or set the stage for subsequent discussions about transitioning to palliative care goals or about withdrawing or withholding life-sustaining treatments. These discussions can also be a way for health care workers to let patients and their significant others know that palliative care and end-of-life care are important topics that the health care worker is willing to discuss.

How to talk about palliative care
Because discussing palliative care with patients and their significant others is an important part of providing high-quality care for patients with life-threatening diseases, these discussions should be approached with the same care and planning that are given to other important medical procedures. For example, 1) Time and thought should be put into the preparations needed prior to holding this discussion; 2) The location of the discussion should be planned; 3) If possible, a preliminary discussion should be held with the patient about who should be present and what will be covered during the discussion; and 4) What is likely to happen after the discussion should be anticipated. These four issues address the processes that ideally should occur before, during and after the discussion. Table 1 outlines some of the steps that may facilitate good communication about palliative care, and these are described in more detail below.

Table 1: Components of a discussion about end-of-life care [84]
I. Making preparations before a discussion about end-of-life care.
- Review previous knowledge of the patient and/or their significant others.
- Review previous knowledge of the patient’s attitudes and reactions.
- Review your knowledge of the disease – prognosis, treatment options.
- Examine your own personal feelings, attitudes, biases and grieving.
- Plan the specifics of location and setting; choose a quiet, private place.
- Have an advance discussion with the patient or family about who will be present.

II. Holding a discussion about end-of-life care
- Introduce everyone present.
- If appropriate, set the tone in a non-threatening way: “This is a conversation I have with all my patients ...”
- Find out what the patient or significant other understands.
- Find out how much the patient or significant other wants to know.
- Be aware that some patients do not want to discuss end-of-life care.
- Discuss prognosis frankly, in a way that is meaningful to the patient.
- Do not discourage all hope.
- Avoid temptation to give too much medical detail.
Make it clear that withholding life-sustaining treatment is not withholding caring.

Use repetition to show that you understand what the patient or their significant other is saying.

Acknowledge strong emotions and use reflection to encourage patients or their significant others to talk about these emotions.

Tolerate silence.

III. Issues that may be of special importance for some patients.

If patients have strong treatment preferences, discuss a living will or other advance directive.

Consider durable power of attorney and the importance of having discussions of treatment preferences, goals and values with that person.

Discuss cultural or religious views, attitudes and preferences.

Consider discussing preferences regarding place of death and preferences regarding burial or cremation.

IV. Finishing a discussion of end-of-life care.

Achieve common understanding of the disease and treatment issues.

Make a recommendation about treatment.

Ask if there are any questions.

Make a basic follow-up plan and make sure the patient and/or significant others know how to reach you for questions.

Making preparations before the discussion

A common mistake that some health care workers make is to embark on a discussion about palliative care with a patient or significant others without having made the necessary preparations for the discussion. Health care workers should review what is known about the patient’s disease process, including the diagnosis, prognosis, treatment options and likely outcomes with different treatments. They should identify gaps in their knowledge by systematically reviewing this information and seek out the information they need before they find themselves in a discussion with patients or their significant others. Health care workers should also be aware of the communication that has occurred with other team members and of the plans for care established or agreed upon by any other care provider responsible for the patient’s care.

It is also important for health care workers to review what they know about the patient and his or her family and social support network, including their relationships with one another; their attitudes toward illness, treatment and death; and their prior reactions to information about illness and death. If, for example, there are significant others who have had strong emotional reactions to bad news, it may be helpful to mobilize the aid of a family member, friend or staff member, such as a social worker or chaplain, who can support them through and after the discussion with the health care worker.

Finally, it is useful for health care workers to consider their own feelings of grief, anxiety or guilt before holding a discussion about palliative care with patients or significant others. This may be especially important when the health care worker has known the patient or significant others for a long time, when the health care worker and patient or significant other have been through a lot together, or when the health care worker has some feelings of inadequacy about the patient’s condition or treatment. Acknowledging these feelings explicitly can help the health care worker avoid projecting his or her own feelings or biases onto the patient or the significant others. In addition, the health care worker’s own feelings of guilt or inadequacy can lead him or her to avoid the patient or significant others or to avoid talking with them about death. Reviewing these feelings by oneself or with another health care worker can be the first step to becoming more comfortable discussing dying and death with a patient or significant other. [16, 198]

An additional step in preparing for an end-of-life discussion is to plan where the discussion will take place and who will be there. Ideally, these discussions should take place in a quiet and private room where there is some assurance that people, phones or pagers will not interrupt the discussion. It should be a room that is comfortable for all the participants without a lot of medical machinery or other distractions, such as medical diagrams. All parties should be sitting at the same level around a table or chairs in a circle. It is best to avoid having a health care worker sitting behind a desk with the patient and significant others in front of the desk. If the patient can participate in the discussion but is too ill to leave the hospital bed, efforts should be made to make the room comfortable for everyone present.

Before the scheduled conference about palliative care, the health care worker, patient and significant others should discuss who should be present for the conference. In addition, the health care worker should make certain that all appropriate members of the staff are consulted about whether they should be present, including the medical staff, nursing staff, chaplains and trainees who have been involved with the patient or significant others. Ideally, someone should take responsibility for scheduling the conference at a time when as many as possible can be present. It may be helpful to suggest that patients and their significant others write down any questions they have beforehand to be sure their questions are answered.

Holding a discussion about palliative and end-of-life care

The first step in a discussion about palliative and end-of-life care is to ensure that everyone participating in the discussion has met everyone else present. For example, some staff members present for the discussion may not have met all family members or significant others. Take the time to go around the room to be sure everyone has met everyone else and knows their role either on the staff or in the patient’s life.

Introducing the issue of palliative or end-of-life care can be a crucial and difficult part of these discussions. Often, by the time these discussions occur, everyone involved knows that the discussion will focus on how to help the patient transition to palliative care goals or even to die in comfort and with dignity. But sometimes patients or their significant others may not be aware that this is a part of the health care worker’s agenda. In those situations, the health care worker should make the patient or significant others as comfortable as possible talking about dying and death.

Not everyone present will have the same level of understanding of the patient’s condition; thus it is often helpful to first find out what the patient and significant others understand of the patient’s situation. This can be a useful way for the health care worker to determine how much information can be given, the level of detail that will be understood, and the amount of technical language that can be used. It can also be useful in some settings to ask the patient or significant others how much they want to hear on this day as a way to gauge how much information and detail to give. Health care workers should avoid unnecessary technical jargon and should be cautious about using technical jargon rather than saying words like “dying” or “death.” Health care workers should also be cautious about using medical detail to cover the uncomfortable message about the patient’s prognosis. However, some patients will be very familiar with technical details and will want sophisticated explanations of their condition. Therefore, it is important to assess the patient’s knowledge and desire for information.
During these discussions, it is important to discuss prognosis in an honest way that is meaningful to patients and their significant others. For example, the term “median survival” is not very meaningful to most people. In discussing prognosis, health care workers should also be honest about the degree of uncertainty in the prognosis. Finally, it is important to provide honest information about the prognosis without completely discouraging hope from those patients or families who would like to maintain their hope. This can be a difficult balancing act for health care workers, but it is a part of the art of holding these discussions. There are several specific ways that health care workers can allow patients or their significant others to maintain their hope in the face of a poor prognosis. First, the health care worker can allow the patient or significant other some time to get used to a poor prognosis. In the acute care setting, sometimes this can take days; in the outpatient setting this can take weeks, months or even years. Regardless of how much time it takes, it can be helpful to patients or significant others if they are allowed to make this transition at their own pace. Second, the health care worker can help the patient or significant other redirect their hope and move them from a hope for recovery to hope for other things such as quality of life in the time that remains, some quality time together, achieving a particular goal, or a comfortable death without pain or discomfort and with as much dignity and meaning as possible.

An important goal of palliative care discussions is to align the health care workers’ and the patient’s or significant other’s view of what is happening to the patient. The discussions about palliative care that are most difficult are ones in which the participants’ views are dramatically different. Making the effort to discover these differences and working to minimize them can be time-consuming, but it is usually time well-spent as it can greatly facilitate decisions about palliative care. This does not mean that health care workers should try to persuade the patient or significant others to accept their views, but rather identify the source of the differences and work toward compromise.

It is extremely important in a discussion about palliative care that the patient and/or their significant others understand that if the decision is made to withhold or withdraw a particular treatment, the health care workers themselves are not withdrawing from caring for the patient. While this may seem obvious to some health care workers, it should be stated explicitly to patients and families to avoid any misunderstanding.

After discussing prognosis and treatment options and the patient’s or significant other’s level of understanding, it is important to spend some time exploring and listening to the patient and family’s reactions to what was discussed. Health care workers should understand that patients and significant others will react to their perception of what was said and that they may not react in the way health care workers expect.

There are several useful techniques that health care workers can use to explore patients’ or significant others’ reactions. First, it can be helpful to repeat what patients or significant others have said as a way to show that the health care worker has heard them and test the health care worker’s understanding. This can be particularly useful when the health care worker and the patient or significant other have different views of what is happening or what should happen. Second, it is important to acknowledge emotions that come up in these discussions. Whether the emotion is anger, anxiety, guilt or sadness, it is useful for the health care worker to acknowledge the emotion in a way that allows the people with the emotions to talk about their feelings.

In acknowledging such emotions, it can be useful for the health care worker to use reflection to show empathy and to encourage discussion about the emotion. For example, a health care worker can say: “It seems to me that you are very angry about the care you have received. Can you tell me why that is?” In this way, the health care worker can show empathy for a patient and allow that patient to talk about his or her feelings. Finally, another technique health care workers can use in these discussions is to tolerate silences. Sometimes it is after what seems like a long silence that patients or family members will ask a particularly difficult question or express a difficult emotion.

Finishing a discussion about palliative and end-of-life care
Before finishing a discussion about end-of-life care, there are several steps that health care workers should make. First, it is important that health care workers make recommendations during the discussion. With the increasing emphasis on patient autonomy and surrogate decision making, there may be a tendency for some health care workers to describe the treatment options to a patient or significant other but to then feel like they should not make a recommendation. On the contrary, it is important that health care workers offer their expertise to patients and their significant others, and part of offering their expertise is making a recommendation. [144] This is especially important in discussions with significant others concerning withholding or withdrawing life support. It is a disservice to leave a significant other feeling like they were alone in making the decision to “pull the plug” on a loved one in situations where ongoing life support therapy is unlikely to provide significant benefit.

Health care workers should summarize the major points and ask patients and significant others if there are any questions. This is a good time to tolerate silence, as it may take some time for the uncomfortable questions to surface.

Finally, before completing a discussion about end-of-life care, health care workers should ensure that there is an adequate follow-up plan. This often means a plan for when the health care worker will meet with the patient or significant other again and a way for the patient or significant others to reach the health care worker if questions arise before the next meeting.

Understanding our own discomfort discussing death
Discomfort discussing death is universal. This is not a problem unique to physicians, nurses, social workers or other health care providers, but has its roots in our society’s denial of dying and death. Medical schools and nursing schools have only recently begun to teach students how to help patients and families through the dying process and still do so in a limited way. [14] Major medical textbooks have had scant information about end-of-life care. [148] For all these reasons, it is not surprising that many health care workers have difficulty talking with their patients and others about palliative or end-of-life care. Furthermore, the medical culture is one of using technology to save lives, and for many health care workers, discussing dying and death is even more difficult in this technologic, aggressive-care era. To compound this difficulty, health care workers can also feel that a patient’s death will reflect poorly on their skills and represent a failure on their part to save or extend the patient’s life.

It is important for health care workers to recognize the difficulty they have discussing dying and death. If they acknowledge this difficulty, they can work to minimize some of the common effects that such discomfort can cause. For example, discomfort discussing death may cause health care workers to give mixed messages about a patient’s prognosis, or to use euphemisms for dying and death, or may even cause them to avoid speaking with a patient or their
significant others. Recognizing this discomfort and being willing to confront it is the first step in overcoming these barriers to effective communication about dying and death. Resources exist to help health care workers address these issues. [16, 198]

Discussing palliative care, dying and death with patients and their significant others is an extremely important part of providing good quality care for patients. While there is little empiric research to guide health care workers in determining the right time or the most effective way to have these conversations, there is a developing experience and an increasing emphasis on making this an important part of the care we provide and an important part of training for students. Much like other clinical skills, providing sensitive and effective communication about palliative care requires training and practice as well as planning and preparation. While different health care workers may have varying approaches and should change their approaches to match the needs of patients and their families, this chapter reviews some of the fundamental components of discussing palliative care and end-of-life care that should be part of the care of most patients with potentially life-threatening illnesses.

The transition to home or hospice care [78]
The focus of this section is planning for and facilitating the transition from curative to palliative care, with emphasis on the initiation of either home-based support services or institutional care. The interdisciplinary team approach is described. Strategies for promoting patient, family and staff education and support will be identified and institutional issues that facilitate or hinder provision of effective palliative care are explored.

The primary goals of palliative care are to maximize the patient’s sense of control, strengthen relationships with loved ones and limit care burdens. [125, 129, 170] The importance of access to appropriate services in the successful delivery of palliative care to the chronically or terminally ill person cannot be overestimated. Knowledge of community resources such as government assistance programs, housing, personal finance, disability benefits, transportation, procurement of durable medical equipment, case management, food and shelter and emergency assistance is essential for helping the patient and family deal with illness, disability and death.

The interdisciplinary team
Palliative care, by definition, is provided by an interdisciplinary team that, in addition to the physician, nurse (including nurse practitioners and nurses), social worker, nutritionist, chaplain and other professionals, includes the patient, family, caregivers and other individuals important to the patient. The interdisciplinary team is a group of individuals working together with a common purpose for the greater good of the patient with advanced disease and his or her family. [41] The goal of the interdisciplinary team is to provide the patient and family with a framework of emotional, physical, spiritual, and social support during the time of advanced disease. [10]

In the United States, the nurse, social worker or case manager often has the primary responsibility for the practical issues discussed in this chapter. It is important, however, that all individuals involved in the care of a person be aware of these issues and be prepared to take the necessary steps to address patient and family needs related to facilitating the transition to palliative care.

While each member of the team has particular expertise, all share responsibility for advocacy, enabling, support, truthfulness and mediation such that crises are prevented, priorities of the patient and family remain paramount, and overall suffering is minimized. Team members share information and work interdependently to develop goals with the patient and family. Information is shared among team members on a regular, organized basis.

In 1999, Cummings described the interdisciplinary team as a group of individuals working together with a common purpose for the greater good of the patient with advanced disease and family. Interdisciplinary team members should include the combined efforts of competent, skilled practitioners who offer confidential, nondiscriminatory, nonjudgmental and culturally sensitive care. Each individual has particular expertise and training and is responsible for making decisions and contributions within the area of their experience and knowledge.

The following sections describe the various roles and functions of palliative care interdisciplinary team members.

Patient and family caregivers
The primary member of the interdisciplinary team is the person who is ill, along with his or her family. Patients and their caregivers need to be active partners in developing and implementing the plan of care in order for the other members of the palliative care team to understand the complex care of families, their advanced care. needs, patient and family caregiver concerns regarding approaching death, and specific bereavement needs. [137] Far too often, health care teams see themselves as the “providers” and the patient and family as simply the “recipients” of their care. Advanced disease care planning cannot be conceptualized in this manner; patients, family members and the interdisciplinary team members must address care planning and support on a mutual, interactive and fluid basis.

Medical providers
Medical providers include physicians, residents, interns, fellows, nurse practitioners and physician’s assistants. Responsibilities of these team members include the following:

- Diagnosis.
- Prognosis.
- Symptom prevention.
- Design of treatment plan.
- Education and communication with staff, patient and family regarding status and response to treatment.

Medical providers’ decisions should be sensitive to cues of advancing condition related and unrelated to lab test values and diagnostic procedures. Consulting physicians are responsible to primary medical providers, and should work as part of the team, not as separate specialists. Specialists may include psychiatrists, ophthalmologists, neurologists, dermatologists, oncologists, gynecologists, orthopedists or providers of any other specialty service.

Nurses
Nurses include staff nurses, nurse practitioners and clinical specialists in adult health, case management, palliative care, mental health, and home and community health. Nursing responsibilities include assessment of patients’ physical and mental capacity for self-care, identification of ongoing care needs, and ongoing education of patients and families. Hospital nurses teach the patient and family throughout the hospital stay and confirm patient and family knowledge prior to discharge in order to enhance comfort, safety and competence in care at home.

Nurses often have the most frequent contact with the patient and family in the inpatient setting, outpatient clinic or at home. It is the nurse’s responsibility to assist the patient in coping with the effects of advancing disease. This includes attention to some of the most personal and intimate aspects of physical care: pain and symptom
assessment and management, personal care such as bathing, control of odor, care of pressure areas, mouth care, bowel and bladder care, as well as patient and family education on anticipated care needs. Nurses also assess the patient’s and family’s level of knowledge of disease, symptom management, comfort care, and how to differentiate emergencies from normally anticipated events and develop a plan for changes in patient status and emergencies. As patient advocates, nurses help ensure, in collaboration with social workers, that the wishes of the patient are met, enabling the dying person and the family to remain involved in key decisions.

**Clinical liaison nurses**

Clinical liaison nurses promote up-to-date communication between providers in the outpatient setting and those in the inpatient unit, particularly for patients who are homebound and require home-based care services. Generally, the nurse’s role is to supervise and monitor concurrent censuses of active patients receiving home care and hospice care services. Specific responsibilities may include the following:

- Monitoring for timely response from home care and hospice agencies for patient care coordination.
- Tracking home care and hospice agency paperwork and medical orders to make sure the medical provider has access to the most current orders.
- Making sure the agency has appropriate medical signatures.

A clinical liaison nurse’s activities also may include daily contact with home-based care supervisors and field staff regarding changes in patient status, streamlining of medication refills, verification of minor orders and facilitation of urgent appointments. Because the care needs can change quickly, the liaison nurse provides troubleshooting for equipment approvals, special service approvals and programs, and contact of care providers. Updating interdisciplinary team members on the complex issues at home for each patient is an important role of clinical liaison nurses in support of the continuum of palliative care.

**Social workers**

The goal of social work in palliative care is to help the patient and family deal with the personal and social problems of illness, disability and impending death, and to provide survivor skill building and support. Social workers assess many important areas of need for both patient and family, and help the family develop realistic plans for the present as well as the future. The strengths and challenges of each family unit are assessed and referrals made to available resources.

Social workers have comprehensive knowledge of community resources, such as housing, finances, disability benefits, transportation, case management, food and shelter resources, emergency assistance, Ryan White CARE Act entitlements, home care, hospice, legal aid, counseling and testing, primary care, emergency assistance, and extended and residential care facilities. If there are no disease-specific resources in the community, the social worker should locate people or organizations that may be willing to provide assistance for the patient and family.

Social workers also assess cultural and sociocultural factors unique to the patient and family, such as use of folk medicine or alternative healing practices in the home, and the family’s ability and desire to care for the patient in a specific setting. The family culture may be unable to accept a death at home and therefore not even the best hospice and personal care attendant support in the home will foster a peaceful death at home. In these circumstances, death in the emergency room or during a return admission to the hospital may be exactly what the family considers the “best death possible.” Social workers can be particularly helpful when there is dysfunction within the family. Social workers can assist with screening for use and abuse, assessment of desire and need for rehabilitation services, and gaining access to such services. One of the most important roles of social workers is advocacy on behalf of the patient and family. Social workers promote continuity of care transitions between hospital and home by arranging residential placement, making referrals to experienced home care and hospice agencies, and arranging for durable medical equipment and supplies. Often social workers play a key role in naming the actual needs of the patient and family.

**Nutritionist**

Nutritionists and dieticians work with patients in all stages of disease, but are most needed as a patient’s condition begins to deteriorate. Nutritional intake and hydration are very emotional issues for family members and interdisciplinary teams. For example, both weight loss and malnutrition increase as HIV disease progresses. Changes in body composition, body image perception, digestion, tolerance of food and side effects from therapies contribute to a reduced quality of life for persons living with some types of advanced disease. Even when patients have adequate food, nutritional knowledge, resources and support, they may be unable to maintain weight. Dieticians can assist with early detection of factors related to impaired nutritional status that accelerate physical decline. Integration of anabolic therapies, nutritional supplements, appetite stimulants and nutritional counseling are important for comprehensive palliative care.

Identification of the point when the nutritional interventions are failing is pivotal for the patient, family and interdisciplinary team members. Nutritional goals are different for the chronically ill and terminally ill patient. Registered dieticians can discuss body composition testing as related to the prediction of the end of life. They are trained to understand and address unique social factors, monitor the effects of disease on body composition and the effects of medications on metabolism, and address the role of changes in body shape in end-of-life discussions with patients and families. Complex nutritional concerns are mediated by active substance use, poverty, dementia, homelessness adolescent motherhood and complex medication regimens. Nutritionists can be valuable in discussions of the pros and cons of end-of-life nutrition and hydration options.

**Pharmacists**

Pharmacists play a critical role in reviewing medication regimens of the treatment plan for up-to-date pharmacokinetics. They assist medical providers with dose adjustments to reduce side effects and increase the efficacy of medications, bring new information to the team, educate patients and families about medication plans, and remain available to assist, evaluate and consult complex care situations.

**Chaplains**

Chaplains are available to assist the patient and his or her family in processing the meaning of illness in their lives as well as their fears, desires and unfinished tasks. Responsibilities of chaplains include being a nonjudgmental resource for referrals for additional community support as desired by the patient and family. Sympathetic chaplains are skilled listeners and able to meet patients and families without judgment. They are key team members in addressing the complex fears, stigma, chronic pain, symptoms and loss. Chaplains provide a special presence with a focus and a stimulus for airing questions of meaning that are invariably present for patients and families with advanced disease. Issues of guilt for past events, feelings of meaninglessness and the need to be listened to are
important concerns for patient and family. Ideally chaplains offer a spiritual presence, not religious. Because so many of the other disciplines of the palliative care interdisciplinary team have many concrete as well as support tasks, chaplains are able to visit without any task agenda and follow the lead of the patient and family on a deep and existential level. Facilitating life review, dealing with regrets, giving thanks for what has brought love and meaning, naming life closure tasks, and preparing for what lies ahead are important responsibilities of this role.

**Physical therapists**
Physical therapists provide physical assessment, education for patients and caregivers, and resources to enable patients to transfer safely, stabilize gait and be mobile. They also assess the need for durable medical equipment. More patients are living with neuromuscular deficits for longer periods of time. Home safety and independence are ongoing goals for the patient and family. In the palliative care setting, a revised physical therapy goal may be to maximize patients’ changing and often diminishing physical resources rather than to improve function.

**Community case manager**
The community case manager collects information about physical and psychosocial functioning and patients’ social environments, develops care plans based on home assessment information and availability of resources, and links patients and families to community services, financial assistance and medical and social services. In addition, a community case manager monitors patients on an ongoing basis, holds case conferences with other members of the outpatient team to evaluate the appropriateness of linked services for patient and family needs, and advocates to reduce barriers to services or generate needed services for individual families. [191]

**The transition of focus from curative to palliative care**
Attention to alleviation of suffering, be it physical, emotional or spiritual, is consistent with the highest aspirations of all health care professions. The integration, therefore, of palliative care with its broad clinical, social and spiritual support into care can promote quality of life and realistic life planning at any time in the course of the illness. There is, however, often a time in the course of care when a formal transition from curative to palliative care is made. In the U.S., because of the peculiarities of financing palliative care services, most often this involves a transition from traditional medical care to hospice care. Integrating palliative care, clinical, social and spiritual support services promotes quality of life and realistic life planning.

Discussions with patients and families about palliative and hospice care can be difficult for even the most experienced providers. Some providers find it useful to keep in mind a sequence of facilitating questions that lead into a discussion of palliative care, first blending discussion of disease-specific therapies with palliative care, moving toward exclusive focus on palliative care, and eventually introducing hospice care. It is also helpful to give patients and families a description of hospice that explains how the care addresses their stated wishes and concerns before the term “hospice” is used, to reduce risk of rejection (see Table 2, below).

**Table 3: Initiating advanced disease planning discussions [85]**
- What has your medical team told you about your condition?
- What does this information mean to you?
- Tell me about your good days. What are you able to do on those days?
- When is the last time you had a day like that in the past two months?
- Have you had any bad days lately? What makes them bad?
- What kind of assistance do you need on these bad days?
- If your condition worsens, do you want to go back to the hospital?
- What are your most meaningful goals at this time in your life? Is there anything we can do to help you achieve them?

Planning for the transition into palliative care must begin with an understanding of the patient and family’s desires and expectations and an understanding of the patient’s illness. In our society, many believe that hospice care means giving up all medications and getting ready to die. Therefore, it is often a mistake to jump directly into a discussion of hospice per se because patients and families unfamiliar with contemporary hospice approaches may attach negative connotations to the term. If the health care provider begins a conversation about hospice care or palliative care without first learning the patient’s perception of his or her status, there is a great chance of the patient refusing such care. It is important that providers assess immediate needs and priorities as stated by the patient and family rather than assume that a problem that is obvious to the providers is of immediate concern to the recipients of care. [17]

The most important goal of intervention at this point is to facilitate discussion so that the patient and family’s responses are as honest and realistic as possible.

**Advanced end-of-life planning discussions**
Each member of the interdisciplinary team must be able to initiate and discuss palliative care, end-of-life care and hospice services. Understanding the patient and family’s perspective on their current and future needs and desires will help guide this planning and referral process. The following questions (Table 3) provide a guide for initiating a discussion about end-of-life-related experiences, desires and planning.
◊ In the event of your death, is there anyone or anything that you are worried about?
◊ Have you ever heard of a medical power of attorney or a health care proxy?
◊ Do you have a living will? Who in your family is aware of it and has a copy?
◊ Are you having chronic pain or other distressing symptoms?
◊ What can we do to make your life more comfortable/ manageable?

Begin by sitting close to the patient (preferably at eye level). Explain that you know he or she has been living with poor health for some time and that you would like to learn more about how he or she is doing. Explain that understanding more about his or her needs will help you advocate for the most appropriate services. Focus on the patient’s perspective on his or her condition, and make sure that you allow the patient to answer the questions rather than giving directive information as you begin this assessment conversation.

**Question 1**
**What has your medical team told you about your condition?**
**What does this information mean to you?**
This question is essential to assessing the accuracy of the patient and family’s understanding of the current medical status and prognostic factors. Often a patient may state that he or she is getting worse, or not getting better, but that the medical team is telling him or her that he or she is going to get stronger. If the patient responds with little emotion or simply restates the medical team’s words, ask, “What is your body telling you about how you are doing?” This question prompts a more introspective response that is always revealing of inner concerns and feelings.

**Question 2**
**Tell me about your good days. What are you able to do on those days?**
The response to this question is equally revealing. The responses of the patient and family will let you know what gives them pleasure. By hearing about unique points of enjoyment and meaning, the team can learn whether and what pleasure activities are available to the patient and family. It is also a way for them to face the realities of how long it has been since they have had several of those good days in a week. Such information helps provide a perspective on the speed of loss of strength and other changes.

**Question 3**
**When is the last time you had a day like that in the past two months?**
This assesses the degree of changes in physical strength, independence and endurance. The most recent holiday is often a period of time that stands out memorably for families. They can recall where they were, what they wore and ate, and how they felt at the end of their activities. Because shortened prognosis is often connected to increasing weakness, helping the patient and family to answer this question aloud helps them state in their own words how and in what ways things may be different now. This begins the patient and family’s personal process of self disclosure about important changes in current energy and needs in the present tense, which enhances realistic planning.

**Question 4**
**Have you had any bad days lately? What makes them bad?**
Health care providers so often are concerned with a patient’s viral load, adherence to medications and weight stability that we forget to ask the patient what defines his or her hard times. Listening carefully to the patient’s response, we learn about not only the patient and family’s priority concerns but also the under-managed symptoms impairing the patient’s quality of life that we may not have been aware of before. Patient and family responses also help to identify areas in which the family may need outside assistance, such as on-call nursing support, child care and respite assistance.

**Question 5**
**What kind of assistance do you need on days when you do not feel well?**
In general, most individuals and families do not like to depend on other people for care and assistance. They often are concerned about being a burden, inconveniencing others, and fearing they will use up their “personal favors” too soon. Give the patient and family permission to fantasize about what kinds of things may be helpful.

**Question 6**
**If your condition worsens, do you wish to go back to the hospital?**
Traditionally, we tell patients, “If you get worse, go to the emergency room.” This is fine if there is an acute infection or event that will respond well to emergency attention. But the person with advanced HIV who has been hospitalized a number of times may already have considered not wanting to come back to the hospital. The patient’s response to this question also helps to guide home-based care options, such as referring the patient to home care or hospice. The patient who is sure he or she wants to return to the hospital is a better candidate for home care where the on-call service is designed for emergency intervention.

**Question 7**
**What are your most meaningful goals at this time in your life? Is there anything we can do to help you achieve them?**
Adults and children all have meaningful life goals. Some people are very open to discussing their goals; others have barely whispered them to their closest confidant if at all. By gaining an understanding of the patient’s goals, team members learn how to plan treatments and care supports. For example, a woman who needs to complete guardianship arrangements for her children may benefit from the support of blood transfusions for temporary strength, whereas a person who has settled his or her affairs might not consider it a benefit.

**Question 8**
**In the event of your death, is there anyone or anything that you are worried about?**
When people think of the possibility of their own deaths, sometimes it is easier for them to think of the needs of others rather than themselves. This pertains to their children and other loved ones as well as cherished pets, plants or any other living things that would suffer during a hospitalization, long-term placement or death. A hospital stay can provide a trial run for future custody or referral information. Sometimes discussing these concerns provides a way for patients to express their anticipatory grief for meaningful aspects of their lives and their need to know that these will be cared for. Discussing such worries can facilitate people’s acceptance of hospice services so that their loved ones can benefit from the social work services and bereavement follow-up.

**Question 9**
**Have you ever heard of a medical power of attorney or a health care proxy?**
Assignment of a health care proxy to make medical decisions on their behalf is an important safeguard for patients to know that their end-of-life wishes will be honored. Patients should select a person who knows and understands their personal desires for quality of life decisions that will affect the direction of their care. Providers
should inform both the patient and his or her health care proxy of the patient’s condition and options for care so they can make decisions from the most informed perspective possible.

**Question 10**  
**Do you have a living will? Who in your family is aware of it and has a copy?**  
A living will demonstrates a clear and deliberate desire not to have life prolonged beyond its natural limits, and most frequently denotes withholding invasive life-sustaining interventions. A true copy of this document should be placed in the patient’s chart in the hospital, group residential facility, extended care and home-based care settings. Patients should be informed whether their state honors this document as a legal determinant of care planning or merely as a guide that can be overruled by their primary provider.

**Question 11**  
**Are you having any chronic pain or distressing symptoms?**  
At an advanced stage of any disease, chronic symptoms not only serve as a reminder of advancing illness and provide a negative distraction from enjoying the limited length of life available, but also become internalized as an intense task of spiritual coping. It becomes impossible for a person to relish quality time with loved ones or complete important tasks if he or she is constantly struggling with nausea, pain, diarrhea, itching or other uncontrolled symptoms. The patient whose symptoms have been very difficult to control may benefit from the palliative symptom management of the hospice team, and such information can be stated in the explanation of hospice care.

**Question 12**  
**What can we do to make your life more comfortable / manageable?**  
Listening to the patient and family’s responses, repeating back their words and letting them know that you have heard them provide powerful validation for patients and families when clear, reasonable requests have been stated. It is most important to respond to their requests as quickly as possible. A response may be as simple as letting the patient go home before the weekend to be with family and completing future tests on an outpatient basis. Or it may be as complex as arranging for minors to visit their loved one in a room with contact isolation.

Only after these questions have been asked and answered is it time to explain hospice and other options for advanced disease care. From the content of this prompted conversation, care planners should have learned about the patient and family’s concerns about the burden of care and approaching death, the presence of distressing symptoms, and after-hour, on-call needs. By listening to the patient and family recall the frequency of good days versus bad, the pace of progression to death can also be estimated. Any ambivalence about returning to the hospital when the patient’s condition worsens should also have been clarified. Finally, the patient and family’s own words, their personal examples of concerns and their identification of life priorities will guide the wording to be used in explaining palliative care, hospice, home care and long-term care planning.

Sometimes, patients and families refuse hospice care at the time it is offered. This is often frustrating for the referrers because they may want the patient to benefit from the clinical expertise, on-call availability, support services and anticipatory grief work prior to active phases of dying. In these cases, we must evaluate the degree to which we have given the patient and family the freedom to choose between home care and hospice with their full understanding of the differences.

Because of the terminal nature of hospice care, young people are often comforted by knowing that if hospice care does not feel right for them, they can go back to standard care. Giving patients and caregivers the permission to think of hospice as specialized care for their current condition and advanced care needs provides great relief because they may have only known hospice as a “last stop before you die,” and with HIV, for example, that is not always true. A gentle personalized explanation of hospice as a care option can often improve acceptance of such services. Care providers must recognize that acceptance of hospice is not the absolute goal of care planning. Assuring patients and families of viable care options that match their values, resources and desires remain our main priority.

**Hospital discharge planning**  
The decision to formally engage home care and hospice care services often occurs during the course of a hospitalization. Prior to each hospital stay, the patient has developed chronic disabling symptoms or new onset symptoms that indicate advancing illness. Increasing fatigue, changing social support and complex home-based care needs require reassessment during each hospital stay. Comprehensive discharge planning is an essential task for promoting the continuum of care. Integration of palliative care services need not be postponed until patients are in the most terminal phase of life.

Elements of comprehensive discharge planning from the hospital setting require an array of assessment, education, support and community referrals. Some of these care elements include understanding the patient and family’s adjustment to illness; understanding an unpredictable illness; sensitivity for the patient witnessing other patients’ declining status; sudden acute, life-threatening illnesses; fear of the unknown; dependence on others; and uncontrolled pain or other symptoms. Interdisciplinary participation in the education of patients and caregivers on important aspects of the patient’s condition, disease trajectory, prognosis and direct care are predictors of improved patient and family satisfaction. [26]

Families need to understand the seriousness of advancing disease and the implications of limited life span for their loved one. One of the major discharge planning problems for families is that it is not always clear when someone is dying. Sometimes, even if a loved one has been in serious and steady decline with wasting, disorientation and a cascade of other symptoms and infections, it can be hard for the closest caregivers to see or admit what is going on. [154] It can make a tremendous difference for physicians, nurses, therapists, social workers and friends and loved ones to acknowledge the approach of death gently, but clearly.

For a smooth transition to home-based care services, discharge planning should begin as early as possible. Evenings and holidays are inappropriate times to discharge a person to home-based care unless thorough arrangements have been made regarding access to ordered medications, equipment, supplies and agency personnel. Referrals to home nursing and palliative care services should be made with much advance notice because it may require several days to secure all services for inpatient teaching and home equipment.

**Assessment for home care**  
One of the most important practical questions facing the patient and team (whether the team is inpatient staff, outpatient staff, or both) is “Can this patient and family live safely at home?” An assessment of the physical and emotional condition of the patient is necessary to understand what needs must be met. This is most often the responsibility of the nurse and/or physician. However, a comprehensive assessment for home care must take an
interdisciplinary approach in addressing several important issues (see Table 4):

- The patient’s mental capacity to make decisions.
- The patient’s physical capacity to carry out activities of daily living and participate in care.
- The caregiver’s capacity to provide support in the home.

Having someone in the role of primary care provider in the home is necessary for patient safety and assistance as well as to coordinate care with the home care or hospice agency, and assess and deal with changing aspects of patient care. Ideally, the primary care provider must be well enough physically and mentally to provide personal care, food preparation, safety supervision, errand running and household management, in addition to being the primary contact for health care providers.

**Table 4: Assessment of the home environment [87]**

- Who in the home can assume primary responsibility as caregiver?
- What is the patient’s level of ability in activities of daily living?
- Are family members or caregiver able to read and understand medication labels?
- What is the family and patient’s understanding of and adjustment to the illness?
- What is the potential impact of disclosure by the patient of health status to family members and other people? Are there physical and mental health issues among other family members and caregivers?
- Are medications, especially pain medications, safe from theft or abuse by others in the home?
- Do the family and caregiver have the capacity to maintain a stable home environment?
- Will the patient be able to access outpatient care from home?
- Will the patient and family be able to obtain medications and supplies at home?
- If the patient is bedridden, is someone available to answer the door, or can a key be provided to the home care providers?
- How safe is the home for patient, caregiver and visiting health personnel?
- Is durable medical equipment such as hospital bed, commode, chair, wheelchair or oxygen needed in the home, and should they be in place prior to discharge?
- Is the home setting appropriate for the patient’s stage of illness?
- What are the financial resources of the patient and family, and have those resources changed dramatically since prior hospitalizations?
- Have legal issues such as guardianship, living wills and health care proxies been addressed, and are they current?
- What care options are there for children during illness and after death of the parent?

If family members have unrealistic expectations of the course of the illness, they may expect that the patient should not be discharged from the hospital until their health is improved. Conversely, the patient, family members and caregivers may be reluctant to have the patient return home from the hospital at all. Often this is due to specific fears that can be addressed in the transition planning process (see Table 5). Some of these fears are real. Others can be ameliorated with education and support.

**Table 5: Common caregiver fears [88]**

- That the health of the family or caregiver will suffer.
- That the patient will be readmitted to the hospital and thereby create a negative perception of the family’s ability to provide care.
- That a crisis will occur at home when no trained professional is on site.
- That incontinence, sickness or confusion will cause embarrassment.
- That the patient will be left out of discussions/decisions regarding care.
- That the loved one will die at home.
- That the illness will have negative impact on the family, especially children, yet the patient’s desire to see them may be particularly strong at this time.

**Home versus institutional care**

Once palliative modes of care are accepted, patients and families need to consider the type of care that matches their needs as well as begin development of a plan for the place of care and the anticipated location of the patient’s death. Most Americans prefer to die at home. [142] An individual can be surrounded by familiar and cherished family, pets and belongings if care is provided in the home. However, there are times when a patient’s need for safety and comfort exceed the capacity of his or her home. The patient may live alone and not have a caregiver; caregivers may be overwhelmed; some people may not have a home to go to; and some home environments may be difficult or impossible for providers to access.

The best outcomes in home-based care are attained when care is provided with the support of others. Even under the best of circumstances, a caregiver needs a solid foundation of support to call on when needed. Although some families manage to mobilize last-minute support networks, the end of life is not a good time to make new personal connections or start support groups. [154] In these instances, professional staff should plan for and assume an even more important role.

In North America, one of the primary goals of palliative care is to support people to die in the comfort of their own homes, and palliative care practitioners hold death in the home as the “gold standard.” [65] However, there are many issues to consider in discharge planning. We must consider the physical dependent care needs, and whether or not the patient and caregivers desire a home death. The physical and emotional devastation of advanced illness makes extraordinary demands upon families and our health care system in relation to the type and level of service required to support end-of-life care at home. [174]

**Home care**

Home care is primarily rehabilitation focused. Skilled nurses provide intermittent, time-limited visits in the home to monitor, instruct in care and perform specific nursing tasks under the direction of the primary physician (activities might include changing dressings, teaching and administering intravenous treatments, monitoring medication adherence and obtaining blood and specimens for laboratory analysis). Home health aides are available for assistance with bathing and personal care (generally two-hour intervals several times a week). Physical therapists are available for gait training, instruction on strengthening exercises, and safe transfer instruction to the patient and caregiver. Social workers may be available for limited visits for assessment and referral for community services, benefits, financial assistance or transfer of the patient to extended care or residential assisted living.

It is important that families, patients and providers have some criteria for selecting a home hospice agency. One of the greatest predictors of successful care is experience. Ideally, families need to know that the chosen agency can address anticipated, predictable symptoms of disease and will have knowledgeable responses to the unpredictable
Hospice care and services
Hospice care is designed for patients living with advanced disease conditions and their families. Education, symptom management, on-call support, care focused on the end of life and bereavement are the cornerstones of hospice care. Symptom management includes ongoing assessments, intervention and follow-up, education and promoting optimal comfort.

Hospice teamwork assists the patient and family to design a personalized plan for disease progression. This plan will address preventing anticipated symptoms, clarifying desires for place of death and related concerns. The focus on symptom control, education and support is to make the patient and his or her significant others as self-reliant and comfortable as possible at home as they plan for approaching death. Care includes skilled nursing (provided by RNs), personal care (by home health aides), social work services, volunteer support, pastoral care and bereavement support for one year after the patient expires. Comprehensive support is key to hospice design. Assessment of and support for physical, emotional, social, financial and spiritual aspects of the patient’s and family’s lives are the priority concerns and focus of care delivery.

Traditionally, only clients who were no longer interested in measures to prolong their lives were eligible for this program. The unique challenges in predicting prognosis and symptom management with advancing HIV disease have pressured some changes in the definitions of HIV hospice care. Specifically, the severity, complexity and unpredictable trajectory of the disease have blurred the distinction between what was previously understood as curative care and what was considered supportive palliative care. [1, 67, 163] At one time, patients were asked to give up all treatment medications, IVs, hospitalizations, diagnostic tests and hopes for recovery. Today, with patients responding unexpectedly to starting and withdrawing of aggressive anti-retroviral therapies, prolonged disease soliloquies, changing prognoses and new hopes, hospice referrals are changing to include more blended care.

Medicare skilled nursing benefit versus hospice Medicare benefit
For patients who have Medicare or Medicaid in states with the Medicaid hospice benefit, choosing hospice can be very complicated. Terminally ill Medicare or Medicaid recipients can choose the skilled nursing benefit or the hospice Medicare benefit. By electing the hospice Medicare benefit, the patient designates the hospice to assume the financial responsibility for all care related to the terminal illness. This obligation provides all the core services of hospice care as well as durable medical equipment, palliative medications, respite care and 24-hour nursing care if needed.

There continues to be ongoing debate regarding the hospice agency’s obligation to continue expensive viral suppressive therapies. Although many of these therapies may provide symptom relief, their cost would exhaust more than the per diem rate of hospice reimbursement.

Ideally, every hospice could benefit from dual licensure as a home care and a hospice agency. An agency licensed for both home care and hospice has more flexibility in care delivery strategies for patients who are continuing to blend palliative care and support with final treatment strategies. This allows the hospice to bill as home care skilled intermittent visits by the hospice nurse and home health aides, as well as other therapies as ordered.

Social services can be billed at the maximum number of visits allowed. The criteria for a hospice referral can include the following:
- The patient is on expanded-access medications, has chronic distressing symptoms, or is experiencing end-of-life distress (patient or family), impaired quality of life secondary to advanced HIV, and/or a life-limiting AIDS-related condition such as CNS lymphomas, recurrent/resistant opportunistic infections, co-infections with other life-threatening conditions such as hepatitis C, and/or end-stage organ failure.
- The patient has become tired of years of complex medication and treatment regimens and failing strategies and wants a simpler and higher quality of life.
- The patient is living with advanced disease and the after-hour call needs exceed those that can be met in the outpatient setting. This may be for symptom management or support. The patient who has come repeatedly to the emergency room may also benefit from the home assessment, education and support that the hospice offers to reduce use of emergency services to address anticipated changes.

Alternative placements
When patients do not have a home to return to or the necessary support is not available, transfer to a residential facility can be a welcome option. Sometimes the home environment is not a safe place for the patient to live alone. There are several alternatives to home discharge. Depending on the available resources in each health care provider’s region, assisted and independent living residential facilities may be available. Skilled nursing homes and extended care facilities may also be available depending on the patient’s location, physical care needs and benefit coverage.

Residential care
Residential housing designed for people with HIV is often a welcome alternative to institutionalized care facilities. A variety of housing models have developed over the years for people with HIV. Although there are several common types of residential models, care should be taken to evaluate support resources available to the patient in each type of home prior to any referral. Scattered-site apartment programs for individuals and HIV-infected families are operated in many locations throughout the U.S. These residences are best suited for those patients who are still able to maintain a high level of independent functioning. [4]

Long-term care
The most common reasons patients are admitted to long-term care facilities are completion of medical therapy; prevention of unnecessary hospitalizations when home care is not available; continuous care needs including dementia-related cognitive and/or functional disability; terminal care when home settings are not available [162]; and, institutional care reimbursement bias since long-term care is less expensive than acute inpatient care.

Skilled nursing care
Sometimes a patient with advancing HIV wishes comfort care only, but is referred to a skilled nursing facility rather than a long-term care facility because of the reimbursement incentives related to restorative care versus long-term care. Medicare skilled nursing facilities cover the costs of skilled nursing and therapies, and many facilities attempt to maximize the number of resident days with this coverage because it is the most lucrative for the skilled care facility. [207] This may offer patients more care therapies such as hydrating IVs, parenteral nutritional and physical therapy.

The skilled nursing facility, the subacute long-term care option, was designed primarily for geriatric populations; and to serve patients
who required skilled nursing care before going home from an acute hospitalization. [156] Skilled nursing care may be more accessible for HIV-infected clients in need of physically supportive care.

**Helpful placement strategies**

Interdisciplinary team social workers will generally be the best resource for placement advice. A well-informed social worker will know about admission criteria and policies of each facility. A thorough assessment of the patient’s social history should reveal any information that may influence housing placement, such as how well the patient handles conflict, anger, frustration and grief. Equally important, providers should be knowledgeable about the patient’s dietary restrictions, mental health, substance use and anti-social behaviors such as confused wandering, sexual relations, public masturbation, stealing or personality disorders causing team and social splitting and chaos. [4]

Encourage the family to visit potential settings and determine which facility feels most suitable in terms of location, attitude of care providers and culture sensitivity.

**Planning for dying**

Planning for death and dying is an important part of caring for the patient and his or her family. Conversations on this topic can be particularly challenging because of the substance of the issues that must be addressed, as well as the difficulties inherent in communication between provider and patient at such a difficult time.

It is particularly important that patients and their families understand that even in some of the most confining situations they have choices. Does the patient want to die at home or in an institutional setting? Who does he or she want as a health care proxy? Who does the patient want to act as guardian for his or her children? Who will care for pets? Who do patients want to be with them at the end of life? One of the greatest losses humans suffer near the end of life is the loss of autonomy. When it is possible, therefore, to give a patient a choice, even in seemingly trivial matters, it is important to do so.

Developing a realistic understanding of the possible ways in which dying may occur improves the likelihood of families making choices consistent with their stated desires. Health care providers can support families by assisting them in visualizing the dying and death of a loved one in broad ways that are meaningful to the patient. [12]

It is particularly important that family members have a clear understanding of what they need to do, whom they can call, and where they can turn when death is imminent. Often, if a plan is not clearly understood, caregivers may yield to the impulse to call an ambulance or bring the patient to an emergency room. This risk is increased if home health aids or other visiting professionals do not clearly understand, providers should be knowledgeable about the patient’s dietary restrictions, mental health, substance use and anti-social behaviors such as confused wandering, sexual relations, public masturbation, stealing or personality disorders causing team and social splitting and chaos. [4]

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**Table 6: Important documents to keep updated and readily available [89]**

- Living will.
- Durable power of attorney or health proxy documents.
- A simple, clear statement of what the patient desires to be done in case of an emergency or crisis (i.e., do or do not call 911).
- Important phone numbers (friends, family, clergy, doctor, nurse, hospice or home care agency).
- Vital statistics (full name, date of birth, Social Security number, mother’s maiden name, place of birth).
- Health insurance and other financial documents.
- Other important documents such as tutorship papers, bank and house papers, safety deposit information.
- Burial policies.
- Caregivers should be encouraged to discuss with their doctors and nurses the symptoms and signs they can expect and what to do when these occur. A clear plan of action to address these symptoms and signs should be developed in consultation with the interdisciplinary team well ahead of the time it may be needed. It is most helpful to make sure that medications needed to manage these symptoms are handy and that a list of all medications is kept up to date. Similarly, an easy-to-access list of important phone numbers (doctor, hospice, nurse, family members, etc.) should be maintained so that, in the event of clinical deterioration, confusion is minimized.

**Supporting the caregivers at home**

Taking care of a loved one can be very frightening if the caregiver does not know what to expect. In addition to understanding the anticipated changes, the caregiver must also know how to promote the patient’s comfort in simple and successful ways. All members of the interdisciplinary team should assist with teaching caregivers, normalizing their care expectations, preparing them for anticipated physical changes and supporting their care delivery.

Ideally, the education of caregivers should begin during clinic or hospital visits before the caregiver assumes full-time responsibility for care. The education of caregivers and family members should include establishing and agreeing on the overall goals of care, the likelihood of symptoms, and the role caregivers play in end-of-life care. Families need to know general principles of pain and symptom management. This includes learning to take symptoms seriously, understanding how the patient expresses discomfort, being knowledgeable about treatment options, and understanding whether interventions have provided relief. Family members also need guidelines for handling themselves appropriately and knowing what sorts of situations require them to contact their health care provider. General symptom control at the end of life should focus on comfort issues, pain, noisy and moist breathing, dyspnea and restlessness. [114]

Caregivers need to be taught to use proxy intensity scales based on their close knowledge of the patient. This enables caregivers to make appropriate comfort choices such as when to administer “as needed” medications and when to increase a dose of long-acting medication, as well as to monitor for new needs. Education of lay caregivers in these skills is an important component of successful discharge planning. Increased caregiver competence in addressing anticipated symptoms can ease caregiver burden and increase the home comfort of both the patient and the caregiver.

As someone approaches the living/dying phase, families acquire additional care tasks and must reorganize the family in order to overcome role strain. [179] This includes a significant change in the household/family leadership order. For example, the caregiver must manage his or her own life as well as become the patient’s bill-payer, personal shopper and child care provider, and act as the patient’s primary social contact and health care coordinator – all of which may not be a practiced or comfortable role for the caregiver.

Most importantly, caregivers need to maintain a sense of competence. Although caregivers cannot be rescued from feeling helpless in the quest to keep a loved one alive, others can assist them in feeling that what they can do is helpful and meaningful. [154] This includes providing assistance with developing meaningful tasks and integrating palliative care team services as care needs advance, and referring patients and families to hospice care (see Table 7).
Table 7: Important comfort strategies to teach lay caregivers at home [90]

Lay caregivers must be as confident and as competent as possible with care and comfort strategies, because in the home setting they will be alone with the patient the majority of the time. These end-of-life related comfort strategies should be demonstrated for, taught to and understood by lay caregivers before they take on their care responsibilities:

- **Give pain and other symptom control medications.**
  Caregivers must be instructed in proper administration and dosing of pain and other symptom management medications at scheduled times to keep their loved one as comfortable as possible. Caregivers should also be instructed in administering rescue medications to be given between long-acting medications.

  When current regimens are not meeting the needs of ongoing comfort control, caregivers should notify their home or hospice nurse to arrange changes in dose or medication(s) to promote patient comfort at all times.

  Caregivers should be informed of the benefits of regular dosing; health care practitioners should dispel caretakers’ myths or concerns about addiction, tolerance and dependence on medications that could inhibit their interest in or ability to adhere to a comfort plan.

- **Keep clean and dry.**
  Keeping bed linens, pillows and clothing dry and clean helps promote a patient’s comfort and dignity as well as preventing decubitus ulcers. Freshening linens with scented powder or light perfume can enhance the olfactory and tactile sense of cleanliness as well.

- **Promote privacy and dignity.**
  As lay caregivers take over more physical care responsibilities, they may need to be reminded to respect the patient’s privacy as much as possible. Instructions such as keeping patients’ private body parts covered and asking guests to leave the room when patients are urinating or receiving bath care will enhance the patient’s dignity and emotional comfort.

- **Care for mouth and lips.**
  When weak or short of breath, patients will breathe through their mouths, which are often relaxed and open. Because this tends to dry out the oral mucosa and lips, caregivers need to brush the patient’s teeth and/or rinse their mouth and rub a cool moist cloth over their teeth and apply moisturizer to their lips regularly.

- **Moisten dry eyes.**
  When the body weakens, eyelids become more relaxed, and people will sleep with their eyes open and rarely blink. This is very drying and sensitive to eye tissue.

  Caregivers should be instructed to avoid directing the breeze of fans, heat and air conditioning toward the patient’s open eyes. Application of two to four drops of artificial tears every one or two hours will add gentle comfort.

- **Reposition and turn.**
  As disease advances and bodies weaken, it becomes more difficult for patients to move and turn themselves. Caregivers can be taught to use a draw sheet for ease and comfort with repositioning.

- **Monitor bowel movements**
  Even though individuals may eat little as they get closer to the end of life, it is still important to remember that bodies continue to make waste. Keeping track of the frequency of bowel movements and notifying the visiting nurse if a patient has not had a bowel movement in at least three days is important for the person’s overall comfort.

  We must remember that the intimate memories of direct care giving by family members become everlasting for the survivors. Informing family caregivers of the natural, expected events and comfort strategies will improve caregivers’ satisfaction with their assistance to the patient.

**Approaching death**

Certain active signs and symptoms of approaching death may be seen in the last several days and hours before a natural and expected death. Caregivers should know that the natural changes as their loved one gets sicker and approaches death may include the following:

- Reduced intake and interest in food and fluids.
- Decreased interest and attention.
- Reduced strength and ability to move.
- Changing sleep and rest patterns.
- Loss of control of bladder and bowels.
- Descriptions of “supernatural” experiences.
- An energy surge.

**Reduced intake and interest in food and fluids**

Caregivers should be taught not to force food or drink into the patient’s mouth or try to use guilt to manipulate the patient into eating or drinking. Small chips of ice or frozen juices may be refreshing so long as the patient can swallow without difficulty. If the patient does want to eat, small frequent feedings of desired foods and fluids may be more manageable and appealing than large meals. The team nutritionist can be very helpful in teaching techniques that may enhance comfort, nutritional quality and feeding assistance with swallowing changes. Most important, families and caregivers need to know that these changes do not cause pain, and that if pain occurs, medical attention is required.

**Decreased interest and attention**

As the body weakens, a person’s involvement with other people, pets, hobbies and other interests may decrease. Individuals may lose interest in favorite activities or topics of conversation. They may want to be alone or with just one person at a time or ask that visits be shorter than usual. Caregivers need to be reminded that the patient is easily tired and weak. Although it is hard for caregivers when they feel shut out, they can be helped to understand that withdrawal from life is a natural part of preparation for death.

**Reduced strength and ability to move**

Families and caregivers need to know that it is natural for a patient to become weak and require increasing amounts of rest to perform even simple tasks. It is important to assist and supervise all of the patient’s activities to promote safety.

**Changing sleep and rest patterns**

As an individual gets closer to the end of life, it is normal for day and night sleeping patterns to reverse. Rest is important for everyone. If the patient is unable to sleep for several nights, pain should be assessed and health care providers should be notified. When fatigue is profound, patients may sleep with their eyes and mouth open and appear unresponsive. Caregivers should understand that this is expected and that, at these times, their role should shift from “doing for” to “being with.” This means that families should sit or rest near their loved ones, hold their hands, apply lotion to their skin, soothe their faces with a warm moist cloth, play music, or converse as the patient would expect them to do.
Most importantly, caregivers should not attempt to awaken the patient by shaking or speaking loudly to them. They should reintroduce themselves to the patient upon every contact and avoid asking “Do you know who I am?” Loved ones experience great pain when they are not recognized and patients may withdraw from interactions if they fear they are causing pain. As the patient responds less, families should continue to speak directly and normally and assume that the patient can hear them, as hearing is the last of the senses to be lost.

**Loss of control of bladder and bowels**

As the body weakens, the amount of urine normally decreases and becomes tea-colored or darker. The patient may lose control of his or her bladder or bowels as the muscles in that area begin to relax. The home care or hospice nurse can determine whether there is a need to insert or apply an external or internal catheter for comfort. Protective measures such as layering the bed or resting area with pads will prevent frequent linen changes and soiling of furniture. Wearing gloves when handling soiled clothing and linens, and washing hands with soap and water before and after personal care, should be demonstrated and instructed. Care should be taken to keep the patient clean and comfortable. The home care or hospice nurse should teach techniques for cleanliness, universal body fluid precautions, skin care and monitoring of bowel patterns.

**Descriptions of “supernatural” experiences**

It is common for many people who are getting closer to dying to describe experiences of feeling that they have been in contact with people who have died before. Generally, these experiences are described as “So and so came to see me” or “I just saw so and so.” Although these may not seem believable to many people, they feel very real to the person experiencing them. For people who have significant anxiety about their approaching death, this is often a time when they may express feeling less frightened. Often people are reported to be resting better and feeling calmer with less emotional strain or struggle after describing this type of experience.

**Energy surge**

It is very common for caregivers to witness a predictable, significant increase in energy and restlessness at the very end of life. This may occur after a period of extreme weakness and deep sleeping, then suddenly the patient becomes VERY alert. The patient may want to stand, walk or sit upright in a chair when they have not done so for days or weeks. Patients may start taking their clothes off and on when they normally were quite modest. They may be found standing naked at the end of the bed. Agitated “picking” at their clothes, bed linens or the air may also be a sign of this stage. Other times the patient may request specific food and eat the entire amount when they have not eaten more than a spoonful of anything for days.

Often this surge of energy confuses and sometimes frightens the individuals closest to the patient. When not educated about the possibility of it occurring, loved ones can interpret this surge of energy as renewed strength and an answer to prayers for recovery. It is important for families to be educated about this possibility, because it is a potential sign that death may occur within the next 24 hours.

**Summary**

Patients and families need reassurance that their interdisciplinary team members are interested in their quality of life, not quantity of life without quality. We must acknowledge a good quality of life as being free of distressing symptoms and offer patients the ability to remain as independent in their lives and care as possible. With comprehensive assessment, we can promote patients’ ability to achieve meaningful goals and take care of personal priorities before the end of their lives.

Deliberate, informed, and conscientious practical actions should be based on understanding the interdisciplinary team role and function, hospital discharge planning, patient and family assessment, and home care and hospice planning. These components are paramount to promoting a continuum of care and support for people and their families at the end of life.

**Ethics in palliative care**

This section presents some of the important ethical issues that arise in palliative medicine. This chapter provides a systematic approach to the ethics of palliative medicine — one that grounds the ethical principles appropriate for this field in the theoretical ideals of palliative medicine.

**Theoretical ideals**

Like other fields of medicine, palliative medicine is informed by theoretical ideals [56, 123] that guide clinical decisions. Two of these ideals are discussed in this section: the ideal of honoring patient dignity and the ideal of promoting patient well-being. Clarity regarding these two ideals is essential in properly framing and addressing some of the most troubling dilemmas that arise in the palliative care context.

The ideal of honoring patient dignity is sometimes identified with the need to respect the patient’s autonomy. Patients in need of palliative care, like other patients, have desires about the kind of treatment they would like to receive. The need to respect these desires grounds a number of clinical duties, some negative and some positive. Negative duties include the duty not to impose unwanted treatment on the patient. For example, if a competent patient refuses life-sustaining therapy, health care workers must not administer it, even if they believe that it is necessary to keep the patient alive. Positive duties include the duty to assist patients in becoming adequately informed about the treatment options open to them. It also includes the duty to assist patients in thinking about the medical treatment they would like to receive should they become incapacitated. This is normally accomplished by encouraging the patient to fill out an advance directive or to appoint a surrogate decision maker.

Respecting patient autonomy is an important part of honoring patient dignity, but it is not the only part. Health care workers should not simply defer to the autonomous desires of their patients, whatever these desires may be. This is obvious in cases where patients ask their health care workers to initiate interventions that are clearly medically inappropriate. If a patient asks his or her health care worker to administer treatment that the health care worker believes would set back the medical interests of the patient, then the health care worker need not provide the treatment. This is particularly important to bear in mind when dealing with patients near the end of life. These patients may ask their health care workers to shorten their lives because they have decided that continued life is no longer a benefit, but a burden. Or they may ask for care that is biomedically futile. For now we wish to point out only that honoring a patient’s dignity may, at times, require the health care worker not to comply with his or her patient’s requests. [197]

This point is easily misunderstood. It is often said, for example, that human life is sacred or inviolable. Regardless of one’s religious views, these expressions refer to the status of human beings as beings that command respect. Health care workers as well as others must respond appropriately to this value. Consider, for example, the case of a patient living with HIV/AIDS who desires to participate in an experimental study with no known benefit and with excessive
risk. A physician might reasonably refuse to enter the patient into the study, even if the patient desires to be enrolled, because the physician believes that to do so would be to fail to honor the patient’s dignity. Of course, it will require ethical judgment to decide how and when a physician should defer to the desires of his or her patients. The point here is that honoring patient dignity is not exhausted by the need to respect patient autonomy.

The second theoretical ideal of palliative medicine is to promote the well-being of patients at the end of life. Patient well-being is promoted by advancing the patient’s interests. But what are these interests? It is useful to divide patient interests into two broad categories. These are:

1. Phenomenological interests (those that directly relate to the actual experience of the patient).
2. Nonphenomenological interests (those that do not solely relate to the actual experience of the patient).

The first category refers to the interests that patients have in being comfortable. A primary objective of palliative medicine is to provide relief for the pain and suffering that often are present at the end-of-life. Although in large measure these experiences are personal and subjective, good palliative care attempts to identify and measure them. Thus, to take just one example, patients in need of pain relief are asked to rank their pain on a scale of 0 to 10. Doing so provides guidance to health care workers who seek to restore them to a level of comfort.

To further the phenomenological interests of their patients at the end of life, then, health care providers must respond appropriately to pain. They must also, however, respond to suffering. The terms pain and suffering are related but are not synonymous. According to a standard definition, pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage. [32] By contrast, suffering is a broader condition – one that includes pain but is not limited to it. An important dimension of suffering concerns the social and psychological consequences that result from the perceived sense of damage to one’s identity. [30] For example, patients often suffer as a result of reflecting on their condition. Illness and disease may cause pain and deterioration in a patient’s physical condition. The patient may then reflect upon the consequences of this for his life and sense of who he is. This may, in turn, lead to further suffering.

Assessing pain

Pain is reasonably well understood. There are standard measures for health care workers to assess pain and standard interventions for relieving it. Suffering is a different matter. It is an ill-defined, controversial and poorly understood experience. As one writer has noted: “There are no agreed-upon and validated standards or measurement instruments for health care providers to assess suffering and to discriminate how much there is. Similarly, there are no clear interventions that should be instituted and no clear understanding of when adequate palliative measures for suffering have been tried and failed.” [58] This uncertainty over the notion of suffering has important ethical implications in the delivery of palliative medicine, and we shall return to it when we discuss the practice of terminal sedation, below.

Much of palliative medicine is focused on the phenomenological interests of patients at the end of life. But the nonphenomenological interests of these patients should not be ignored. These are interests that are not well characterized in terms of maintaining the patient’s comfort. A patient’s interest in having his privacy respected or in remaining alert even if his pain is not fully controlled are examples of such nonphenomenological interests. These are discussed here because recent studies suggest that it is easy for health care workers to overlook them. [182] Taking these interests seriously often requires health care workers to engage in active deliberation with their patients about their treatment options.

The two theoretical ideals of palliative medicine that have been discussed – the ideal of honoring the dignity of the patient and the ideal of promoting the patient’s well-being – will sometimes come into conflict. Not everything that furthers the interests of a patient is compatible with honoring him as a being worthy of respect. Determining how to respond appropriately to these potential conflicts forms an important part of the ethics of palliative medicine.

Mediating principles

The theoretical ideals of palliative medicine guide health care workers in determining which interventions and treatment options are appropriate for their patients. But on their own, these ideals cannot resolve the ethical problems that arise in the palliative care setting. These situations require recourse to ethical or mediating principles. The term mediating is used because they intercede between the theoretical ideals discussed above and the concrete cases health care workers encounter.

There are several important ethical principles that are relevant to the practice of palliative medicine. This chapter will discuss three of them:

1. The principle of deliberation.
2. The rule of double effect.
3. The principle of proportionality.

Each of these principles has been discussed in the medical ethics literature. [11, 61, 103, 105, 112, 145, 181]

Before discussing these principles, a few words of caution are in order. First, the three principles here are not the only ethical principles relevant to palliative medicine. Given the space constraints of this chapter, we cannot present an exhaustive discussion of these principles. However, these three are very important, and an understanding of them should provide an understanding of how ethical principles can be applied to concrete cases in palliative medicine. Second, some of the principles that we will discuss – and in particular the rule of double effect – are controversial. We shall, however, indicate to the reader when we advance claims that not all medical ethicists would agree with and we shall provide references to alternative points of view.

The principle of deliberation

The principle of deliberation concerns the manner or process by which health care workers communicate with their patients. According to this principle:

Health care workers should take an active role in eliciting from the patient the patient’s own understanding of his condition and the values that may or may not bear on its treatment. This dialogue should be critical and deliberative. It should be based on the recognition that patients often do not have fully formed values and that they often make mistakes in thinking about how their values translate into particular treatment decisions.

This principle relies on a particular model of shared decision-making. Therefore, to explain this principle more fully, we must say a few words about shared decision-making in general. Shared decision-making depicts medical decision-making as a collaborative process regulated by a division of labor between physician and patient. [20, 61, 105, 112] In this process, the role of the health care worker is to use his or her training, knowledge and experience
to provide facts to the patient about the patient’s diagnosis and prognosis if alternative treatments (or the alternative of no treatment) are pursued. [20] By contrast, the patient’s role is to bring his or her values and preferences to bear on the assessment of these alternatives. In this way, shared decision-making enjongs patients to participate actively with their physicians in reaching decisions about treatment goals and options.

Shared decision-making is particularly important in palliative medicine. It has been well documented that good patient care at the end of life closely correlates with the willingness of health care workers to engage in discussions with their patients about prognosis and goals of care, advance directives, when to forgo specific treatment or diagnostic interventions and concerns about family support. [123, 182] Applied to these specific areas, the model of shared decision-making can help health care workers honor the dignity of their patients and promote their well-being. [164]

This is true in two respects. First, in many areas of palliative medicine, there is a large measure of discrete discretion in decisions about which interventions are appropriate for specific patients. For example, there is no uniform appropriate response a physician must give to his or her patients regarding when to forgo medical interventions, how to best initiate an advance directive, or the most appropriate method for relieving end-of-life suffering. Accordingly, the correct or most appropriate response to these issues will be known only after the physician has engaged in a process of careful questioning designed to elicit the patient’s goals and expectations about the dying process. Indeed, with respect to these issues, the quality of patient care will depend largely on the skill of the health care worker in reaching an understanding of the patient’s values and needs and coaxing them into clarity. [123, 164, 182, 203]

Second, the preparation and approach to death involves patients in a series of unique and novel experiences. The health care provider, in contrast, will probably have cared for a number of dying patients and be much more familiar with the dying process than will his or her patient. [164] Because every patient dies only once, and every death is a new experience, [164] there is a special justification for shared decision-making between the health care worker and patient in the palliative care context. Through shared decision-making, the health care worker can promote patient well-being by realistically describing to the patient what he or she can expect from the dying process. Although the health care worker may not be able to predict with certainty when a patient is going to die, shared decision-making enables the health care worker to assist the patient in setting reasonable and achievable goals. This model of decision-making also enables health care workers to identify mistaken beliefs that their patients may hold about what they should expect from the dying process. For example, some patients with AIDS-related pain may hold the belief that their pain is inevitable and that it is improper or useless to report it. [103, 106, 200] Collaborative discussion with their physician is necessary to identify and correct these mistaken beliefs.

The extent to which shared decision-making serves the ideals of honoring patient dignity and promoting patient well-being turns, in part, on how the role of the physician is conceived in the decision-making process. On this matter, there are competing understandings. [61] One might argue, for example, that physicians should provide their patients with adequate information and then simply let the patients decide for themselves which course of treatment should be undertaken. Against this, we believe that physicians – at least physicians in palliative medicine – should adopt a more deliberative stance with their patients. This means they should initiate a reflective and critical dialogue with their patients about how the patient’s values and preferences bear on the treatment options available to them. The point of such a dialogue should be to help patients come to reasoned decisions about the treatment options they face. [103]

It is important to understand that the principle of deliberation does not direct physicians to correct, modify or change their patients’ values. Rather, it asks health care providers to take an active role in stimulating patients to deliberate about their values in a reasoned and well-informed manner. The goal of this is to improve the understanding of both the physician and the patient.

One objection to deliberative decision-making might be that it seems unduly time-consuming, hence, clinically inappropriate. The fact that there is no uniquely correct treatment option for many situations at the end of life further underscores the importance of deliberation in this context. Depending on the values and preferences of patients, a regimen that is good for one patient may be inappropriate for another, even though both have the same underlying diagnosis. Accordingly, in many instances, to determine the correct regimen for a particular patient, the physician will need to engage the patient in deliberative decision-making. [103] For these reasons, then, a strong case exists for holding that the principle of deliberation should be a fundamental ethical principle guiding palliative care.

The rule of double effect

Deliberative decision-making helps health care workers honor patient dignity and promote patient well-being through a process of reasoned dialogue that identifies, clarifies and, where necessary, helps their patients to modify their preferences for care at the end of life. However, taken by itself, the principle of deliberation is insufficient for ethically appropriate palliative care. While the principle of deliberation enjongs health care workers to discuss their patients’ preferences with respect to end-of-life care, it offers no guidance on the type of ends or goals that health care workers may permissibly advance. Nor does it speak to the issue of when it is permissible for health care workers to refuse to comply with the desires of their patients that emerge in the deliberative process.

These limitations to the principle of deliberation are important. They reinforce the point that health care workers are not ethically required simply to defer to the autonomous desires of their patients, whatever these desires may be. Indeed, as was stressed earlier, honoring a patient’s dignity may, at times, require the health care worker not to comply with his or her patient’s requests. These considerations suggest that health care workers must be capable of bringing other ethical principles to bear on the deliberative process.

One such principle that has special relevance in the palliative care setting is the rule of double effect. This rule has a long history in moral philosophy and in medical ethics. [11, 19, 105, 145, 181] In palliative medicine, it is most frequently invoked by health care professionals to explain the moral difference between administering high-dose pain medication to a patient and euthanizing a patient as a means to treating his suffering. [11, 128, 181] According to the rule of double effect, the essential difference between these two acts rests on the important distinction between an intended effect and an unintended side effect of a clinical intervention. In the instance of administering high-dose pain medication to a patient and euthanizing a patient as a means to treating his suffering. [11, 128, 181] According to the rule of double effect, the essential difference between these two acts rests on the important distinction between an intended effect and an unintended side effect of a clinical intervention. In the instance of administering high-dose pain medication to a patient and euthanizing a patient as a means to treating his suffering. [11, 128, 181] According to the rule of double effect, the essential difference between these two acts rests on the important distinction between an intended effect and an unintended side effect of a clinical intervention. In the instance of administering high-dose pain medication to a patient and euthanizing a patient as a means to treating his suffering. [11, 128, 181] According to the rule of double effect, the essential difference between these two acts rests on the important distinction between an intended effect and an unintended side effect of a clinical intervention. In the instance of administering high-dose pain medication to a patient and euthanizing a patient as a means to treating his suffering. [11, 128, 181] According to the rule of double effect, the essential difference between these two acts rests on the important distinction between an intended effect and an unintended side effect of a clinical intervention. In the instance of administering high-dose pain medication to a patient and euthanizing a patient as a means to treating his suffering. [11, 128, 181] According to the rule of double effect, the essential difference between these two acts rests on the important distinction between an intended effect and an unintended side effect of a clinical intervention. In the instance of administering high-dose pain medication to a patient and euthanizing a patient as a means to treating his suffering. [11, 128, 181] According to the rule of double effect, the essential difference between these two acts rests on the important distinction between an intended effect and an unintended side effect of a clinical intervention. In the instance of administering high-dose pain medication to a patient and euthanizing a patient as a means to treating his suffering. [11, 128, 181] According to the rule of double effect, the essential difference between these two acts rests on the important distinction between an intended effect and an unintended side effect of a clinical intervention. In the instance of administering high-dose pain medication to a patient and euthanizing a patient as a means to treating his suffering. [11, 128, 181] According to the rule of double effect, the essential difference between these two acts rests on the important distinction between an intended effect and an unintended side effect of a clinical intervention. In the instance of administering high-dose pain medication to a patient and euthanizing a patient as a means to treating his suffering. [11, 128, 181] According to the rule of double effect, the essential difference between these two acts rests on the important distinction between an intended effect and an unintended side effect of a clinical intervention. In the instance of administering high-dose pain medication to a patient and euthanizing a patient as a means to treating his suffering. [11, 128, 181] According to the rule of double effect, the essential difference between these two acts rests on the important distinction between an intended effect and an unintended side effect of a clinical intervention. In the instance of administering high-dose pain medication to a patient and euthanizing a patient as a means to treating his suffering. [11, 128, 181] According to the rule of double effect, the essential difference between these two acts rests on the important distinction between an intended effect and an unintended side effect of a clinical intervention. In the instance of administering high-dose pain medication to a patient and euthanizing a patient as a means to treating his suffering. [11, 128, 181] According to the rule of double effect, the essential difference between these two acts rests
to apply the distinction. [128] Indeed, research suggests that lack of certainty in this regard results in inadequate control of distressing pain symptoms in terminally ill patients. [37, 128] Because the distinction between an intended act and an unintended side effect is crucial to understanding the rule, it will be helpful to begin by considering a simple illustration, one that is not controversial and one that is not related to medical practice.

Consider the difference between the strategic bomber and the terrorist bomber. [19] Both are engaged in a war and both drop bombs that result in the deaths of innocent civilians. However, the strategic bomber, unlike the terrorist bomber, does not intend to kill any innocent civilians. He bombs a munitions factory, and although he is aware that doing so will have the side effect of killing innocent civilians, he does not intend to kill them. The terrorist bomber, in contrast, intentionally kills the innocent civilians as a means of weakening the resolve of the enemy. It is widely believed that the action of the terrorist bomber is morally worse than that of the strategic bomber. The rule of double effect explains why this is the case.

In medicine, physicians rely on the distinction between an intended effect and an unintended side effect all the time. For example, when a physician treats streptococcal pharyngitis with penicillin, he or she foresees the possibility that the patient may develop an anaphylactic reaction and die. [181] It is clear, however, that the intent is not to kill the patient. The foreseeable death of the patient in this kind of case would be an unintended side effect of the intervention.

Not every medical ethicist believes that the principle of double effect is as important to medical practice as is stressed here. [145] For example, it has been claimed that the rule of double effect is weakened because the intentions of health care workers are inherently ambiguous. [145] Even if this were the case, it is most often clear both to health care workers and to others what their intentions are. And when it is not clear what their intentions are, morally reflective health care workers will make some effort to clarify them.

We have said that the rule of double effect rests on a distinction between an intended effect and an unintended side effect of an action. Although it has been formulated in different ways, the full statement of the rule reads as follows:

An action with two possible effects, one good and one bad, is morally permitted if the action:

- Is not in itself immoral.
- Is undertaken only with the intention of achieving the possible good effect, without intending the possible bad effect even though it may be foreseen.
- Does not bring about the possible good effect by means of the possible bad effect.
- Is undertaken for a proportionately grave reason. [181]

The statement on the rule of double effect notes four conditions that can be understood by returning to the example of the physician prescribing penicillin for streptococcal pharyngitis. The physician is intending to bring about a good effect: the destruction of the bacteria streptococcal pharyngitis. This action is not itself immoral. Indeed, it is an action that any competent physician would undertake in these circumstances. It therefore satisfies condition 1. The physician also does not intend the bad effect, although he may foresee it as a possibility. He realizes that there is some chance that the penicillin will kill the patient, but bringing about this possible bad effect is not part of his intention to act. His action therefore satisfies conditions 2 and 3 as well. The only remaining issue, then, is whether the physician’s intervention was done for a proportionately grave reason. This means that if the intended good effect of the intervention is significant, and if the foreseeable bad effect is either less significant or very unlikely to occur, then the intervention will count as one undertaken for a proportionately grave reason. Because the possibility that a patient will die from penicillin is very remote, the physician’s intervention in this example satisfies condition 4.

The same analysis can be applied to distinguish aggressive pain management from euthanasia. Administering high-dose pain medication has both a possible good and a possible bad effect. The possible good effect is the relief of the patient’s suffering. The possible bad effect is that the intervention will hasten the patient’s death. If a physician were to administer the medication with the intent only of achieving the possible good effect, then his action would not be in itself immoral. It would satisfy conditions 1 and 2. If the patient’s suffering were sufficiently intense, and if it were of the kind that is appropriately managed by pharmacological interventions, then the physician’s intervention would be undertaken for a proportionately grave reason and would therefore satisfy condition 4. This leaves only condition 3. Unlike euthanasia, aggressive pain management does not aim to bring about the possible good effect by means of the possible bad effect of the intervention. In short, aggressive pain management does not kill the patient as a means to relieving his suffering; rather, it administers medication to relieve his suffering that may have the foreseen, but unintended, bad effect of hastening his death.

In the previous section it was stressed that one of the theoretical ideals of palliative medicine is to honor the dignity of the patient. We claimed that this means that patients inherently have a status that commands respect. This status, in turn, grounds limits on how physicians may respond to their illness or disease. The rule of double effect adds content to this requirement in that it implies that physicians must never intend bad effects when treating their patients. This includes never intending to make one’s patients dead. This point has particular relevance in the discussion of terminal sedation and its implications for the proper treatment of patients, including patients at the end of life. When this rule of double effect is properly applied, distinctions can be made that make clear the difference between physician-assisted suicide or euthanasia and appropriate treatment of intractable pain (which risks hastening death).

The principle of proportionality
The rule of double effect is somewhat controversial. Not every medical ethicist believes that it is as important to medical practice as we have suggested. [145] But the fourth condition in the rule of double effect – the one that specifies that a physician must act for a proportionately grave reason – is widely accepted even by those who reject the rule of double effect. Therefore, it can and should be considered on its own terms. So understood, we shall refer to it as the principle of proportionality.

This principle is very important to palliative medicine. A number of writers have appealed to this principle in their explorations of when and under what conditions a physician’s obligation to relieve terminal suffering may justifiably override his or her obligation to prevent harm. [11, 146] According to Timothy Quill, Bernard Lo and Dan Brock, for example, the concept of proportionality requires that the risk of causing harm bear a direct relationship to the danger and immediacy of the patient’s situation and expected benefit of the intervention. [146] These writers have proposed the following formulation of the proportionality principle for regulating physicians’ use of vigorous pharmacological measures in the palliative care setting.
The greater the patient’s suffering, the greater risk the physician can take of potentially contributing to the patient’s death so long as the patient understands and accepts the risk. [146]

This formulation of the principle, however, does not specify what type (or types) of suffering justifies a physician’s use of pharmacological interventions to treat suffering. It simply instructs physicians to sum up the total amount or intensity of the suffering their patients are experiencing. In this formulation, all terminal suffering is on equal footing, and it is all subject to the requirements of proportionality.

This principle of proportionality can be extended and refined by considering the theoretical ideal of promoting patient well-being and distinguishing between different kinds of pain and suffering and the different sorts of therapeutic interventions they may require. For example, a patient living with HIV/AIDS who is nearing the end of life may experience suffering that results from his terminal condition as well as suffering that results from his own reflection on his condition. Suppose, for example, that this patient blames himself for his illness and this causes him great inner turmoil. The resulting psychosocial suffering may be as intense as or even more intense than the pain and suffering caused by his underlying physiological condition. It would be a mistake, however, simply to sum up his suffering as if it were all the same. Some of the suffering that this patient experiences – what we have referred to here as psychosocial suffering – is not appropriately managed by aggressive pharmacological measures. Unless these thoughts are symptoms of major depression, the patient’s psychosocial suffering should be managed by appropriate psychological or spiritual counseling.

A reformulation of the principle of proportionality that takes these issues into account follows:

A physician’s therapeutic response to terminal suffering is justified, even if it foreseeably hastens the patient’s death, if and only if:

- The measures implemented properly correspond to the intensity of the patient’s suffering.
- The measures implemented are appropriate for the type of suffering the patient is experiencing.
- The patient understands and accepts the risks associated with the measures. [105]

Clearly, the word “appropriate” in the second clause of this principle is crucial. It should be understood in light of the interest the patient may have in being restored (as much as their condition permits) to a state of psychosocial well-being. As has been suggested, one important way in which this interest can be ignored is when physicians prescribe high-dose narcotics to treat psychosocial suffering. Such interventions are effective in the sense that they alleviate suffering, but they are inappropriate in that the restorative interests of patients are ignored or set back.

The requirement that the therapeutic measure be appropriate to the kind of suffering the patient is experiencing calls for discrimination on the part of the physician in diagnosing suffering. In particular, it enjoins the physician to attempt to distinguish between the pain and suffering that is caused by the underlying physiological condition of the patient and psychosocial forms of suffering. [30, 72, 101, 105]

Additionally, this modified principle of proportionality requires physicians to recognize the limits of their medical authority. Physicians can fulfill their duty to relieve certain types of suffering by relying solely on pharmacological measures, but these measures are inappropriate responses to other forms of terminal suffering that are likely to be experienced by patients. With respect to psychosocial suffering, patients may need other measures, such as counseling or spiritual support. [27, 30, 101, 105] Some physicians are skilled in providing these interventions, but many are not. For those who are not, they best fulfill their obligation to relieve this kind of terminal suffering by involving other members of the palliative care team in the care of the patient.

The modified principle of proportionality therefore differs significantly from the simple formulation of the principle of proportionality introduced at the beginning of this section. It provides a more precise response to the specific types of ethical dilemmas surrounding pain and suffering that health care workers are likely to encounter in the palliative care context. These include dilemmas surrounding the use of terminal sedation and other measures that go beyond routine clinical interventions. Different types of suffering at the end-of-life may call for different therapeutic interventions. Thus, to comply with this reformulated principle of proportionality, physicians must develop skill in working as a member of an interdisciplinary team as well as in diagnosing and appropriately attending to the different types of suffering present at the end of life. The training health care workers should receive to develop these clinical skills is addressed in detail in other chapters of this guide.

Determining when physicians should violate their patient’s interest in confidentiality or when physicians can and should administer high doses of sedating medication to dying patients are challenging and complex matters that require sound clinical comprehension of the patient’s condition, good ethical judgment and an understanding of the ideals and principles that have been discussed. Although certainly not definitive, the discussion of these cases has shown how the theoretical ideals of palliative medicine inform certain fundamental ethical principles, which in turn provide guidance in clinical cases.

We have not discussed a number of issues that raise important ethical problems for palliative care workers, such as issues that surround decisions to withdraw or withhold medical interventions. To be sure, the principles that we have discussed in this chapter are relevant to these issues. For example, according to the rule of double effect, a physician should not withhold food and fluids from his patient as a means to hasten the patient’s death. Nonetheless, he/she could withhold or withdraw feeding tube treatment from a patient whose medical condition had made him unable to eat if the treatment were disproportionately burdensome, even if this would foreseeably (but unintentionally) shorten the lifespan of the patient. We have not attempted to provide a full discussion of these issues here.

Grief and bereavement [75]

The experience of a death of a loved one can be one of profound sadness and loss. The multidimensional responses to a loss are all part of the grief process. This section will explore the nature and process of grief and identify interventions for use by the palliative care team in helping the bereaved cope with their losses, adjust to a changed life and be open to personal growth and transformation.

The language of grief

Grief is the normal, dynamic process that occurs in response to any type of loss. This process encompasses physical, emotional, cognitive, spiritual, and social responses to the loss. It is highly individualized, depending on the person’s perception of the loss and influenced by its context and concurrent stressors. [122]

Mourning is often used interchangeably with grief, but mourning more specifically refers to the public expression of grief. This public expression (perhaps crying or wailing) does not necessarily relate
Bereavement is the state of having suffered a loss. This incorporates the period of adjustment in which the bereaved learns to live with the loss. The root of the word “bereaved” means to be robbed of something valuable. [151]

Complicated mourning arises from an interrupted or obstructed grief process. Rando [151] uses this term to refer to potentially harmful outcomes, from somatic discomfort to chronic emotional distress and even the possibility of death when grief is unaccommodated. There are risk factors that can lead to complicated mourning.

**Anticipatory grief**

Grief responses do not begin at the death of the loved one; rather, they begin as soon as symptoms develop that people perceive as life-threatening. Lindemann referred to these responses as anticipatory grief. [116] However, the anticipatory grief does not replace the necessity of grieving after the death. [22] Rando delineates these responses from post-death grief and asserts that the term anticipatory grief is misleading because “anticipatory” connotes future losses, whereas in actuality, people are dealing with past and present losses as well. [153]

Anticipatory grief includes changing assumptions, adapting to role changes, finding a balance for staying separate from, yet involved with, the patient, and experiencing feelings of sadness, depression and anxiety. [149] The patient and caregivers have the opportunity to absorb the impending loss gradually over time. Often the people involved must change their assumptions about the way the world works and what their future will hold. Statements such as “I always thought …” or questions like “What will I do?” and “How will I live?” are examples of this process.

Patients and caregivers also struggle with secondary losses: loss of health, security, employment, relationships, meaning and the future. As the disease progresses, the losses increase and intensify. Facing these losses can be overwhelming for all involved. [50]

One benefit of this process is the opportunity for people to complete unfinished business, whether practical, emotional or spiritual. The opportunity to get affairs in order, make wishes known, prepare for final arrangements, reconcile with loved ones, express gratitude and say goodbye can be meaningful for the patient and the caregiver. [149]

If the illness is prolonged, the period of anticipatory grief may become problematic. Those caring for the person may emotionally withdraw too soon and experience ambivalence about the length of the illness and caregiving responsibilities. This can lead to feelings of guilt during the illness and during bereavement. [205]

There have been conflicting studies as to whether the opportunity to grieve before the death impacts the bereavement process by lessening the length of bereavement and/or easing the pain of grief. [97] Worden notes that grief is multidimensional and it would be too simplistic to claim that a time to prepare for the death of a loved one correlates positively with a shortened bereavement period. [205]

However, the palliative care team should be aware of the process and common themes that emerge during anticipatory grief because the responses may have an effect on caregiving and the patient’s emotional status. [205] Brown notes that suffering surrounds loss and death over the entire illness trajectory. [22]

Health care professionals can facilitate the anticipatory grief period by:

- Identifying and legitimizing feelings of sadness, anger, guilt and anxiety.
- Encouraging the expression of feelings in private, comfortable settings.
- Redefining terms related to expressions of grief (“lose control” or “break down” can be reframed into “emotional releases,” which are normal, expected aspects of coping with stress and grief).
- Enabling people to complete unfinished business.
- Encouraging people to live fully and enjoy life whenever and wherever they can.

As people face their death, they want to know that they will be remembered and that their life had meaning. Engaging patients and caregivers in life review and memory work are effective interventions in coping with anticipatory grief. [52] Zulli suggests religious rituals, meditation, use of photography and videos, and journeys (one last trip to a favorite place) as therapeutic tools. [208]

**Factors that affect the grief process**

Several factors affect the length and intensity of the grief process. These may help or hinder the bereaved move through the grief process.

**The nature of the relationship between the deceased and the bereaved**

This is a crucial factor during the grief process. Generally, the greater the bond between the deceased and the bereaved, the greater the grief experienced. The type of bond (parent, child, partner, sibling) does not necessarily indicate the intensity of grief; every relationship is unique. However, the death of a child is usually always considered a high risk for the bereaved parent(s). [151] If there was an ambivalent or codependent relationship, this can also complicate the grief process, as the bereaved may face intensified emotional responses. [205]

Additionally, young children, the elderly and the developmentally disabled are often considered unable to comprehend the loss, therefore unable to grieve. Anyone who is able to create a bond is able to grieve when that bond is threatened or broken. [51] Often these disenfranchised grievers need additional support due to the risk factors experienced during their loss and yet are denied even general sympathy from society. Some are excluded from the post-death rituals, denying them an opportunity to say goodbye to their loved one and limiting the social support at a crucial time. [205]

**The manner of death**

The perception of preventability of the death is a crucial factor that can complicate the grief process. If the bereaved believe the death could have been prevented, the risk for a complicated grief process increases. [151]

Length of illness is another important factor. Chronic or prolonged illness often means the entire family structure is changed in order to accommodate care. People may have to rearrange work schedules or not work at all; they may need to find additional caregivers and/ or financial support. These stressors on the family system can also complicate the grief process. [151] As treatment advances, health care professionals may find that their anticipatory grief and bereavement period are affected by closer bonds that have developed wherever they can.

Encouraging people to live fully and enjoy life whenever and wherever they can.

**Symptoms and side effects of the disease may also affect the grief process.** Doka identifies two symptoms that correlate positively with complicated grief: disfigurement and mental disorientation. [52] The challenge of coping with these symptoms can create ambivalence and premature detachment from the patient.
The time of death experience is an individualized factor. Some may experience increased guilt if they were not able to be present at time of death; some may experience increased distress depending on their perception of the dying experience.

**Social variables**
A key indicator in how the bereaved will cope is the availability and use of a good support system. The support system may include family, friends, coworkers, neighbors, religious communities, pets and professional support. Many families come to rely on the support of the health care team during the patient’s illness; in fact, due to the disenfranchised nature of the death, other typical sources of support may be lacking. Once the patient has died and the health care team is no longer regularly involved, the family is coping with not only the death of a loved one, but the loss of their main support as well. Reinforcing or feeding into the anger felt by the bereaved at the lack of family and community support only further distances them from potential sources of future support. Rather, encourage and strengthen connection with family, friends and the community.

Cultural and religious beliefs and practices may provide comfort for the bereaved, but may also intensify grief responses. Regardless of cultural and ethnic background, the family of origin plays a significant role in how the beliefs inform the bereaved’s coping style. Familiarity with the beliefs and practices of other cultures and religious groups will provide a general framework for the palliative care team. [7] Cultural differences should be considered before judging a person’s grief style as “abnormal” or “pathological,” but stereotyping grief responses of an individual based on a cultural group can be inaccurate and offensive. [54] It is best to ask the individual person how their beliefs and practices are affecting their grief process.

The personality traits and coping style of the bereaved will also impact on the bereavement period. There is no “right” or “wrong” way to grieve (as long as it is not harmful to the bereaved or another); the key is to find ways that work for that particular person. Some people will never shed a tear publicly; others will cry every day for months. Talking about the loss and expressing feelings related to the death can be very healthy for some people, yet threatening for others. Doka and Zucker are exploring different styles of grief and define a continuum of grieving styles from highly intuitive (process, feeling-oriented) to highly instrumental (linear, task-oriented). [53] Identifying styles on the grief continuum will have implications for grief support. For example, a highly instrumental griever who is focused on cognitive responses and benefits from accomplishing tasks may not find a bereavement support group that encourages expressions of feelings particularly helpful. [17]

Some communities are coping with a disproportionate number of deaths. This can lead to bereavement overload, when the bereaved experience a series of losses and accumulate unaccommodated grief that may lead to unhealthy physical, emotional and spiritual responses. [108] In addition to experiencing the deaths of many loved ones and friends, the bereaved may also experience other losses. These losses may include loss of their community, loss of meaning and purpose, loss of privacy, loss of role in society. Coping with bereavement overload and multiple losses increases the risk of a complicated grief process. [151]

Other stressors that can complicate the grief process are mental health issues, substance abuse issues and problems with physical health. It would be important to refer the bereaved for appropriate medical evaluation in these circumstances.

Again, it is important to note that grief itself is not pathological, but the factors noted above can interfere with or complicate the grief process. Various terms have been ascribed to obstructed grief: “morbid, atypical, pathological, neurotic, unresolved, complicated, distorted, abnormal, deviant, or dysfunctional.” [151] The inconsistency of terms mirrors the issues in defining and treating grief that has been complicated. [151]

**Tasks of the grief process**
Many grief theorists use attachment theory to develop their understanding of how grief works. British psychiatrist John Bowlby proposes that human beings tend to make strong affectional bonds with others as part of a need for security and safety. [18] When these bonds are threatened or broken, strong emotional reactions occur; we name these responses grief. Recent grief theorists have built on Bowlby’s work. There are distinctions among each theory, but most include an initial phase of shock or numbness, a time of disorganization and a process of reorganization.

These traditional models have been challenged in recent years. One issue is the use of “stages” to describe the grief process; this term implies a passive reaction to loss, and critics assert that moving through grief is an active process. [152] Some believe that traditional models focus too heavily on emotional responses to loss and de-emphasize cognitive responses. [53, 152, 206] Another concern is that in these models, the aim of the grief process is for resolution, or a return to the premorbid state of being. Rando encourages the term accommodation rather than resolution, recovery or completion. [151] Accommodation implies an active process of adapting to fit specific circumstances rather than a linear process with a final endpoint. Recent models of bereavement highlight grief as a dynamic process around which certain themes can be distinguished and personal growth and transformation emerge as possible outcomes. [136]

The work of William Worden is used to illustrate the grief process in this chapter. His “tasks of mourning” are a way to understand the grief process more fully. [205] The word “tasks” is used intentionally to emphasize that dealing with the responses to grief takes effort; hence “grief work.” Worden acknowledges that the tasks do not have to follow a specific order, and that people can work on more than one task at a time.

**Task I: Accept the reality of the loss**
The first task of grieving is to acknowledge and accept the reality that the person is dead and will not return. This task can take time, as the bereaved often experiences a period of numbness, shock and disbelief even if the death was expected. [205] The bereaved may experience a period of searching or yearning for their loved one. Some people report they expect to see their loved one when they arrive at home, or attempt to contact them by calling out or reaching for the telephone before remembering that the person is gone. Many people find themselves continuing their old routine, such as setting the table for two people even though one spouse/partner has died. The bereaved may even refer to their deceased loved one in the present tense or use the present and past tense together in the same conversation. These are all examples of working to accomplish the first task: accepting the reality of the loss.

Traditional rituals such as funerals or memorial services can help people accomplish this task. This public method of saying good-bye helps people confront the finality of the death. Often the first visit to the cemetery reinforces the finality of the loss as well.

The primary aim of grief support at this task is to help people accept the reality of the loss in their own time and at their own pace. It may
take days or weeks for the reality to be accepted, even longer for it to be fully absorbed.

**Task II: Experience the pain of grief**

The second task of mourning is for the bereaved to allow the pain of grief some form of healthy expression. The pain of grief includes physical, emotional, behavioral, cognitive, spiritual and social responses to the loss (see Table 8). This task is crucial because if the bereaved cannot, or do not, acknowledge the pain of grief in some way, these responses could manifest themselves in unhealthy ways. [205]

**Table 8: Common reactions to grief [80]**

- **Physical:** Dizziness • breathlessness • hollowness in the stomach • tightness in the throat/chest • dry mouth • changes in energy level • loss of sexual desire.
- **Emotional:** Numbness • yearning • sadness • anger • guilt • anxiety • loneliness • relief.
- **Behavioral:** Indecisiveness • sleep disturbance • changes in appetite • absent-minded • social withdrawal • crying • sighing • searching • increased use of alcohol, tobacco or tranquilizers.
- **Cognitive:** Disbelief • confusion • sense of “going crazy” • preoccupation with the deceased • sense of presence.
- **Spiritual:** Search for meaning • loss of faith • comfort from God • alienation.
- **Social:** Passive • hyperactive • withdrawn • unpredictable mood swings.

Coping with the pain of grief will be unique to every individual. These responses are common themes that occur during bereavement; not every person will experience every response.

People do experience actual physical responses to a loss. Although Stroebe reports that the physical health of the bereaved is at risk after a loss, many of the symptoms reported to physicians during bereavement are normal, expected responses to grief, not pathological. [180] This can lead to inappropriate use of health care services. [143]

Emotionally, people tend to experience a wide range of feelings. The initial shock and numbness usually subside after a few weeks or months and thoughts and feelings that were present all along begin to surface. Many bereaved report significant emotional responses six months after the loss as the reality is fully absorbed: “I thought everything was fine, but now I feel like things are worse.” While some people need to express their feelings and talk about the loss repeatedly, others do not experience grief emotionally as their primary response, and therefore, do not need to process their feelings. Some may even experience dissonance if painful feelings are experienced but are unable to be expressed: “I may appear normal on the outside, but on the inside, I’m screaming.” [52]

Sleep disturbances and appetite changes are some of the most common behavioral responses to grief. Behavioral responses may vary due to cultural and gender factors, but most cultures include crying as an acceptable response to death. [54] The bereaved should be wary of the risk of increased use of alcohol, tobacco, and tranquilizers. [143]

Recent grief theories are emphasizing the cognitive responses to loss. [136, 152] This may be the primary way some people experience grief (the “instrumental griever.” [53]) Initially, many bereaved report a fear of “going crazy;” education and normalization of the grief process may help assuage this fear.

Spiritual responses to loss are also highly individual. Even those who have a strong spiritual or religious belief system may not be comforted by their beliefs. One of the crucial aspects of the spiritual response to loss is the ability to make meaning from the experience. [136, 159]

**Task III: Adjust to the loss**

The third task refers to the work of developing the skills and filling the roles necessary to move forward without the deceased being physically present. [205] Usually this task can begin only after several months of dealing with the loss. It may include adjusting to living alone, being a single parent, getting a job, learning to manage finances or taking on household tasks.

Some bereavement support groups use the image of Janus, the Roman god of departures and returns, beginnings and endings, as a symbol for their group. This two-faced god, who looks both forward and backward, is an appropriate symbol for this task as the bereaved struggle with looking back to acknowledge what has been lost and beginning to look ahead to see what is possible in their lives.

Part of adjusting to the loss is facing all the significant “firsts” that occur in the first year of bereavement. Coping with the first holiday, birthday or anniversary without the loved one can trigger a temporary upsurge of grief. [151] Grief responses can be triggered by cyclic precipitants, such as holidays or anniversaries, linear precipitants that are one-time occurrences related to experiences or age (i.e., not being present at an important function), and stimulus-precipitated precipitants, including reminder-inspired reactions (“we always used to...”) and music-elicited reactions. [151] An upsurge of grief may include a return of physical symptoms, various emotional responses, changes in social behavior and spiritual distress. These temporary reactions must be distinguished from complicated grief and should not be misdiagnosed as pathological responses.

**Task IV: Reinvesting energy from the deceased into new life**

The fourth task of mourning refers to the ability to transfer the emotional energy invested in the relationship with the deceased into new, healthy approaches to life. [205] This does not mean that the deceased is now “forgotten” or that the bereaved has “obtained closure.” Rather this task refers to the bereaved’s ability to establish a new connection with the deceased, one that can transform their new life. Browning explains this concept as “Saying good-bye to grief, without saying good-bye to the loved one.” [23]

Reinvesting the emotional energy into new life may include a variety of methods. Simple gestures, such as considering the deceased’s perspective in a difficult situation, or wearing a locket with a picture of the deceased are examples of this reinvestment. Others reinvest the energy outward in sociopolitical actions, such as working for justice, fundraising or creating a memorial for the deceased.

Signs that a person is learning to accommodate his/her grief include:
- A return to good health (or their health status before the death of their loved one).
- Acknowledgment of the reality of the loss.
- Redefined identity.
- Emergence of new skills or roles.
- Establishment of or reconnection with a social support system.
- Ability to cope effectively with temporary upsurges of grief.
- Comfort with the quest to find meaning.
- Personal growth/transformation.

Those who grieve the death of a loved one never truly “get over” the loss. Even after people accomplish the tasks of grieving, the pain of the loss is still present, though hopefully less intense and more manageable.
Unique aspects for children
As noted earlier, children are often disenfranchised grievers because they are considered “too young” to understand what has happened. The age, intellectual and emotional developmental stages, and circumstances of the loss will all affect the child’s grief process. Wolfelt notes that initially, children often experience shock and disbelief, then experience similar physiologic responses to adults: fatigue, changes in sleep patterns, appetite changes, headaches, tightness in the throat. [204] They also tend to experience a wide variety of emotions and cognitive responses. One unique aspect of children’s grief is regressive behavior (such as wanting to nurse, sleep with a parent, use baby talk, suck their thumb even though they have not exhibited such behavior for a while). Wolfelt attributes this to a desire to return to an earlier time when the child felt protected and secure. [180] He also describes the phenomena of a child approaching grief “in bits and pieces” – crying or calling out for the loved one and then returning to play within minutes. This coping mechanism works well for the child but can be difficult for the family to understand.

Often children will “act out” in an attempt to get attention. Even if a child is not able to comprehend the loss, she can respond to the changes in the emotional status of the family. Developmentally, children must come to understand that death is final, irreversible, inevitable, unpredictable and universal. They must also perceive the concept of nonfunctionality and deal with causality. [204] Table 9 illustrates children’s developmental stages, possible responses and suggested interventions.

Table 9: Children’s developmental stages [81]

<table>
<thead>
<tr>
<th>Age</th>
<th>Thoughts</th>
<th>Feelings</th>
<th>Actions</th>
<th>Interventions</th>
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</table>
| 0-3 months | • Loved one will return.  
• Loved one is just away. | • Confused.  
• Anxious.  
• Fearful of separation.  
• Sad or angry. | • Cry.  
• Exhibit clinging behavior.  
• Exhibit regressive behavior. | • Hold the child.  
• Offer words of reassurance in a calm tone of voice. |
| 3-5 years | • Wonder if loved one can return.  
• Deceased can still function.  
• Their actions or words caused death. | • Confused.  
• Anxious.  
• Fearful of separation.  
• Sad or angry.  
• Fearful they might die, too. | • Cry.  
• Temper tantrum.  
• Nightmares.  
• Exhibit regressive behavior.  
• Exhibit clinging behavior. | • Provide extra attention.  
• Offer reassurance calmly, don’t worry about the “right words.” |
| 6-9 years | • Understand finality and irreversibility of death.  
• Their actions or words caused the death. | • Confused.  
• Anxious.  
• Withdrawn.  
• Lonely.  
• Guilty. | • Exhibit aggressive or impulsive behavior.  
• Engage in risky or dangerous behavior.  
• Decline in grades.  
• Difficulty concentrating. | • Provide extra attention.  
• Tell the truth, but give only appropriate information.  
• Reassure the child they were not responsible for the death.  
• Encourage physical or artistic expression of grief.  
• Maintain structure, limits and rules.  
• Use children’s books about death to normalize feelings. |
| 9-12 years | • Understand finality, irreversibility, nonfunctionality of death.  
• Their actions or words caused the death. | • Sad.  
• Confused.  
• Anxious.  
• Withdrawn.  
• Lonely.  
• Guilty. | • Exhibit aggressive or impulsive behavior.  
• Engage in risky or dangerous behavior.  
• Decline in grades.  
• Difficulty concentrating. | • Provide extra attention.  
• Tell the truth, but give only appropriate information.  
• Reassure the child they were not responsible for the death.  
• Encourage physical or artistic expression of grief.  
• Maintain structure, limits and rules. |
| 12-18 years | • Understand finality, irreversibility, nonfunctionality of death.  
• Their actions or words caused the death. | • Sad.  
• Confused.  
• Anxious.  
• Withdrawn.  
• Lonely.  
• Guilty. | • Exhibit aggressive or impulsive behavior.  
• Engage in risky or dangerous behavior.  
• Decline in grades.  
• Difficulty concentrating. | • Seek community and school support.  
• Maintain structure, limits and rules.  
• Encourage physical or artistic expression of grief. |
In interactions with children, health care workers should:

- Consider themselves a source of emotional support for children as well as adults.
- Encourage children to ask questions about death and dying and discuss their feelings.
- Encourage families to include children as participators in the events associated with death.
- Explain that grief is associated with the capacity for love.

Different families have different beliefs regarding death. Adults may not want you to share your personal religious or cultural beliefs with their children. When speaking to children, be honest and stress that your ideas may not be shared by everyone. Children are usually able to express grief if significant adults in their life provide an example.

Children usually appreciate the special circumstances surrounding death and appreciate being treated as a responsible member of the mourning family. In speaking to children or answering their questions, the following guidelines may be useful:

- Explain the truth in simple terms. Do not avoid using the words “death” or “dead.” You might say that a very sad thing happened, then explain the circumstances surrounding the death in general terms (for example, saying the individual was ill, or was in an accident, or was very old). Explain that death is no one’s fault, and that the person will be missed very much by the people who loved him or her.
- If a child’s parent dies, reassure them that the surviving parent is not likely to die.
- Be honest. Children have a great capacity to handle the truth. Encourage them to ask questions.
- Offer reassurance that you will be there to help them recuperate from the grief.
- Do not postpone explaining facts surrounding a specific death or the topic of death in general.
- In some cases, children may consider themselves fully or partly responsible for the death of someone close to them, believing that something they said or did influenced the death. Reassure children that they could not have caused the loss of the deceased, explaining that thinking something cannot make someone sick or cause their death.
- In talking of death, avoid describing death as a long journey, which can reinforce feelings of abandonment by a loved one, or saying that the deceased is “asleep” forever, as a child may develop trepidation associated with going to bed at night.
- If the child wishes to attend the funeral, explain to him or her beforehand what will take place and what they will see and do, describing the open or closed casket and rituals surrounding death. Explain that many people will be crying and expressing their grief because they are saddened by the loss.

It is generally considered healthy for adults to express feelings of grief in front of children, as this gives the message that grief is normal, rather than the implication that there is something wrong with grieving openly. Children can learn that parents may be sad at times, but that this is a normal response and is in no way a rejection of the children. Adults should be encouraged to share their thoughts and feelings related to the loss, and understand that grieving is something shared by a family.

One can usually determine rather quickly if a family is emotionally “open” or “closed.” Some families allow and encourage the full spectrum of emotion in its members; some do not. In addition, some families accept children’s capabilities to understand death at their own level and view children as integral in the family grieving process. In emotionally open families, children are allowed to ask questions, and the occasion of death becomes an opportunity for emotional growth of the child.

Emotionally closed families are explicitly or implicitly discouraged from showing certain emotions, including grief. Parents may exert subtle pressure on children to deny or hide their feelings. The message in these families is that everyone mourns the same way, and there is no need to discuss the thoughts and feelings associated with the loss of the loved one. In some cases, the expression of grief is interpreted as irrational or inappropriate. Children in emotionally closed families may never learn to express their grief, which can express itself in emotional and physical distress of other kinds.

Support for the bereaved

The palliative care team can provide support to the bereaved by acknowledging the loss, sharing memories of the deceased, normalizing grief responses and encouraging good self-care. [121, 122] To do so, the palliative care team should be familiar with the dynamics of the grief process and be able to identify healthy and unhealthy coping behaviors.

Immediately after the death, it is important to reach out to the bereaved, acknowledge the loss, and give permission to grieve. After the death of a patient, families appreciate general expressions of condolence and sympathy. Telephone calls, cards and notes are all appropriate responses from the health care team.

An acknowledgment of the death and expression of sympathy are meaningful, but another way the health care professional can help the bereaved accept the reality of the death (Worden’s Task I) is by providing details and information about the illness, as appropriate. Many families do find it helpful to meet with the physician or members of the health care team after the death of a loved one to review the course of treatment or ask questions about the plan of care. The bereaved need reassurance and affirmation that they did everything possible to help their loved one and they did not hasten the death of their loved one (perhaps by administering the “last dose” of medicine or providing inadequate care). Malacruda reported survivors are often not satisfied with the information provided about the cause of their loved one’s death. [120] It appears that the communication and information provided to the bereaved by the palliative care team may also influence their bereavement recovery. [119]

Some people may not need or want further contact with the palliative care team. It may be a painful reminder of the illness and death, especially if they have not accepted the reality of the loss. Take cues from the bereaved before assuming they wish to remain in contact.

Educating about the grief process and normalizing appropriate grief responses can lessen some of the stress and anxiety experienced by the bereaved as they face Worden’s second task of mourning – experiencing the pain of grief. Often the image used to describe the grief process is that of a “roller coaster ride.” This image highlights that those moving through grief do not necessarily feel better and stronger each day, but experience “ups and downs” and “twists and turns” that are normal for the ride. The bereaved need to learn what typical physical, emotional, spiritual, cognitive and social responses they can expect, but also be allowed to experience and express their own process.

- Reassure them that it is normal to experience upsurges of grief related to significant days or events such as birthdays, anniversaries, and holidays, as well as some upsurges that will occur at random.
- Explain to them that anticipation of the significant day is usually worse than the day itself.
Encourage them to divert the energy from worrying about the significant day into making plans for how to spend the day.
Remind them that the grief journey takes as long as it takes; there is no time frame for grief.

Tables 10 and 11 suggest techniques for supporting the bereaved during the grief process.

### Table 10 [82]

<table>
<thead>
<tr>
<th>What to Say:</th>
<th>Because This:</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I’m sorry.”</td>
<td>Acknowledges the loss. A lack of response or acknowledgement is hurtful to the bereaved.</td>
</tr>
<tr>
<td>“I don’t know how you feel but I do care about you.” “I’m sorry that you are hurting.” “I can’t imagine what you are going through right now.”</td>
<td>Acknowledges the pain the bereaved is experiencing and affirms your care for them.</td>
</tr>
<tr>
<td>“Go ahead and cry. It’s okay. I’m here for you.”</td>
<td>Gives permission for expression of grief and offers reassurance of support.</td>
</tr>
<tr>
<td>Refer to the deceased by name.</td>
<td>Bereaved often fear that people will forget their loved one. It does not upset them more to hear the name of the deceased; the worst has already happened.</td>
</tr>
<tr>
<td>Share specific stories that you remember about the deceased.</td>
<td>Validates the importance of the life of their loved one. Offers reassurance that the person will not be forgotten.</td>
</tr>
<tr>
<td>Use open-ended questions: “How has losing your partner to AIDS affected you?”</td>
<td>Allows for individualized responses.</td>
</tr>
<tr>
<td>Use superlative phrases in questions: “What has been the worst part for you?” “What has been the most helpful?”</td>
<td>Encourages the bereaved to prioritize and focus.</td>
</tr>
<tr>
<td>Use third-person statements to initiate the conversation: “Some people tell me that coping with loneliness is the most difficult thing for them. What has it been like for you?” or “Many people tell me they find it difficult to concentrate. What has your experience been?”</td>
<td>Normalizes grief responses but also invites individualized responses.</td>
</tr>
</tbody>
</table>

### Table 11 [83]

<table>
<thead>
<tr>
<th>What NOT to Say:</th>
<th>Because:</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I know just how you feel.”</td>
<td>Even if others experience a similar loss, every relationship is unique. No one knows exactly how the bereaved feel.</td>
</tr>
<tr>
<td>“You’ll get over this in time.”</td>
<td>People do not “get over” their grief. They can learn to manage it and learn to adjust to life. Many bereaved equate “getting over it” with forgetting their loved one.</td>
</tr>
</tbody>
</table>

What NOT to Say: | Because:
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>“Don’t cry.”</td>
<td>Though meant as reassuring, this is often perceived by the bereaved as an attempt to “shut down” their grief.</td>
</tr>
<tr>
<td>“It was God’s will” or “God knows best.”</td>
<td>This can offend nonreligious people and even religious people may not be comforted by this. Avoid clichés.</td>
</tr>
<tr>
<td>“If you need anything, call me.”</td>
<td>This puts the effort on the bereaved. Since most people experience decreased energy during bereavement, they are unlikely to call.</td>
</tr>
<tr>
<td>“You should be glad she/he didn’t suffer more.”</td>
<td>The length of time a person suffers is irrelevant to the bereaved; their focus is on the death of that loved one.</td>
</tr>
</tbody>
</table>

Good self-care is a significant part of learning to adjust to the loss (Worden’s Task III). Remind the bereaved the grief affects their entire person, physically, emotionally, cognitively and spiritually. Encourage physical exercise (as appropriate), proper diet and proper rest. Explore their spiritual responses to their losses and accompany them as they search for meaning. Know that they are not looking for external answers; they need to find their own answers or learn how to live with the questions. Help them develop the creative aspect of their being by encouraging them to keep journals or incorporate art and music techniques as part of working through their grief. [165] Strengthen their support systems and be aware of the community resources in the area. Nord notes that “social support, community involvement, and fostering a sense of purpose are useful” in learning to accommodate a loss. [138]

At various points along the grief journey, it may be appropriate to encourage use of ritual. Van de Hart states that rituals can provide therapeutic expressions that symbolize transition, continuity and healing. [196] Therapeutic bereavement rituals are usually rituals of transition or continuity. [151] Rituals of transition may relate to the separation of the loss or the transition to adjusting to life without the loved one. These symbolic actions may include writing letters to the deceased and then perhaps burning them, taking off a ring or melting it into another piece of jewelry, and putting away photographs of the deceased. Transition rituals may be most appropriate during Worden’s Tasks I and II. Rituals of continuity may be related to the transformed relationship with the deceased as a new type of connection is established. [151] These rituals may include visits to the grave, mentioning the deceased’s name during a prayer or creating a square for the AIDS quilt, and may be most effective during Tasks III and IV.

The elements of a ritual include the people involved, the symbols to be used, the ritual action and the characteristics of the ritual. The ritual, like the grief process, is a personal experience and must be created for the individual. It will arise from the circumstances, the personality, and the beliefs of the bereaved. [151]

It is possible to experience personal growth and positive transformation through the grief process. Trends indicate that people who are able to create meaning in the death have a sense of connectedness with life and are flexible in coping with change are likely to be positively transformed by their grief. [159] Neimeyer builds his grief model on constructivism, asserting that humans need to find meaning and organize their lives around basic assumptions.
The grief process can be a time to explore this more deeply. [135] The health care team can help facilitate this process, recognizing that positive transformation develops as people move through the grief process and should not be expected within the initial grief response. Three questions can be raised to help the bereaved work on this transformation process: [157]
1. What do you want to bring from your old life into your new life?
2. What do you need to leave behind?
3. What do you need to add?

In summary, interventions suggested to help people coping with death include:
- Reaching out to the bereaved.
- Giving the bereaved permission to grieve in ways that work for them.
- Normalizing responses to grief.
- Educating about the grief process and what to expect, especially during the first year.
- Encouraging good self-care.
- Referring for appropriate medical evaluation.
- Encouraging use of creative techniques such as keeping a journal, art and music.
- Encouraging use of ritual.
- Exploring spiritual responses, especially the search for meaning.
- Strengthening and encouraging use of a support system.
- Affirming efforts to re-engage in life.
- Helping the bereaved recognize opportunities for personal growth and transformation.

In reaching out to the bereaved, the palliative care team may experience their own issues of grief and loss. This is a normal response; the important thing is to confront these issues separately so that one can be fully present to the bereaved in their time of need. It may be appropriate to cry with or in front of the bereaved as long as they do not have to comfort members of the palliative care team. Health care professionals have a responsibility to process their own grief work in order to be present to others who are grieving. Good self-care and identification of healthy, appropriate coping mechanisms are essential.

It is also important for the palliative care team to maintain a therapeutic perspective in reaching out to the bereaved. Remember:
- No one can take away the pain of grief.
- Don’t let a sense of helplessness prevent outreach to the bereaved.
- Recognize the value of “being present” to the bereaved.
- Develop empathetic listening skills. [151]

Mallinson notes that in addition to addressing grief issues, health care professionals must also address the concurrent stressors – substance abuse; mental health issues and the effects of homophobia, racism and stigmatization – and advocate for accessible services and community resources. [122]

Palliative care is a holistic approach to medicine that does not end with the death of a patient. Caring for the bereaved is a responsibility and a privilege. In many deaths, the bereaved face significant issues that can complicate their grief process. Interventions that incorporate a holistic approach to grief and loss can facilitate the bereavement process, possibly improving the bereaved person’s ability to function, reducing some of the pain experienced, and providing an opportunity for transformation. [122]

Final medical care in palliative patients [79]

Ventilator withdrawal for intubated patients

In instances like fatal pneumocystis carinii pneumonia, mechanical ventilation may be withdrawn in order to discontinue futile and invasive medical treatment. These decisions are complex and involve ethical principles of withdrawing life-sustaining treatments that are well established. [21, 155] In particular, it is important that health care workers establish with the family and, if possible, the patient, that the goal of withdrawing ventilator support is to remove a treatment that is no longer desired or does not provide comfort to the patient. Health care workers need to work to develop a consensus among the health care team in order to withdraw ventilatory support; it is seldom an emergency decision, and time should be taken to resolve disagreements and concerns among the team and family. This procedure requires informed consent discussions, especially to inform family members that patients may not die immediately after ventilation is withdrawn.

A protocol developed by experienced critical care physicians appears below:

Table 14: Protocol for ventilator withdrawal [91]

<table>
<thead>
<tr>
<th>Step</th>
<th>Specific actions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prepare the family and patient (if conscious).</td>
<td>Hear concerns, address fears, establish informed consent, explain procedure so they are prepared, give family a place at the patient’s bedside if they wish.</td>
</tr>
<tr>
<td>Appropriate setting and monitoring.</td>
<td>Provide privacy to the greatest degree possible in the ICU setting. Turn off all monitors. Remove tubes, drains and associated machinery if possible without compromising comfort. Liberalize visitation as much as possible.</td>
</tr>
<tr>
<td>Ensure adequate sedation.</td>
<td>Establish continuous infusions of analgesia and anti-anxiety medications; provide wide latitude in drug dosing to nurses who have experience in evaluating suffering in patients who cannot talk.</td>
</tr>
<tr>
<td>Reduce inspired oxygen to 21 percent (air).</td>
<td>This should be done in steps, with adequate time to ensure that any dyspnea or air hunger is controlled with the morphine infusion; if the infusion is increased, bolus doses should be given to rapidly establish the new steady state.</td>
</tr>
<tr>
<td>Remove positive end expiratory pressure (PEEP).</td>
<td>Air hunger must be relieved before proceeding with morphine.</td>
</tr>
<tr>
<td>Set ventilator to IMV or PS level to fully meet patient’s ventilatory needs.</td>
<td>This provides another period to establish patient comfort before proceeding.</td>
</tr>
</tbody>
</table>
Extricate or leave on humidified air T-piece.

Offer the family the possibility of private time with the patient if feasible, or support from any staff members they wish to have present. Rituals devised by the family or preferred by clergy may have an important role.

Department of Health & Human Services, Health Resources & Services Administration, 343-376.

After death care

Time of importance to respect the patient’s and family’s cultural, religious and spiritual beliefs throughout the course of care up to and including, the time of death and beyond. Every attempt should be made to allow the person to die where they feel most comfortable. Even in a clinical setting, being able to be with the person who is dying is very comforting to most family members. Every attempt should be made to remove unnecessary monitors such as pulmonary oximetry readers, intravenous lines, cardiac monitors and even ventilators when possible; see guidelines above for removing ventilatory support.

Those in attendance may appreciate a pastoral caregiver who can lead in prayer, or they may want to sing and to wait for the “sigh” to leave the room. Ritual cleansing, bathing with oils or other cultural practices should be encouraged. Even after the family has gone and the body has been removed, it is advisable to leave a silk or “spirit” to leave the room. Ritual cleansing, bathing with oils or other cultural practices should be encouraged. Even after the family has gone and the body has been removed, it is advisable to leave a silk or “spirit” to leave the room.

Memorial rituals

Scrapbooks, video tapes, poetry and other creative efforts can help those who mourn to express these feelings and to link children or other family members who may have a tangible means of remembering the deceased. Other traditions of remembrance include planting a tree, building a shrine, or placing a tomb marker.

Syndrome of multiple losses

Mourning one death is complex and can extend for months or years. For the AIDS epidemic, many gay men suffered the deaths of 10 or more friends; mothers may have lost several children; and inner-city dwellers have often lost loved ones to violence and disease. [38] When there are multiple losses to grieve one after another, the individual does not have adequate time to complete the usual bereavement tasks. People can develop a protective response that may cause them to shut down emotionally and to be unable to experience significant feelings of either a positive or negative nature. [34, 122, 167] Clinically, this may look like a post-traumatic stress disorder and usually requires professional help for resolution.

Works Cited

Final Examination Questions

Choose True or False for questions 1 through 10 and mark your answers online at www.elitecme.com.

1. The palliative philosophy comes from a model of care that is very similar to the familiar, hierarchal and physician-dominated model that characterizes much of contemporary medical care.

   True   False

2. In acute care settings, social workers often play an important role in identifying and contacting significant others, coordinating and scheduling family conferences and keeping in contact with significant others during the hospital stay.

   True   False

3. It is best for health care workers to put aside their own feelings of grief, anxiety or guilt before holding a discussion about palliative care with patients or significant others.

   True   False

4. Health care workers should not acknowledge anger, anxiety, guilt or sadness in the patient or patient’s significant other during a discussion about palliative and end-of-life care.

   True   False

5. One of the primary goals of palliative care is to maximize the patient’s sense of control.

   True   False

6. In 1999, Cummings described the interdisciplinary team as a group of individuals working together with a common purpose for the greater good of the patient with advanced disease and family.

   True   False

7. Two of the five most common reasons patients are admitted to long-term care facilities are completion of medical therapy and prevention of unnecessary hospitalizations when home care is not available.

   True   False

8. The patient’s significant other will generally be the best resource for placement advice.

   True   False

9. Keeping track of the frequency of bowel movements and notifying the visiting nurse if a patient has not had a bowel movement in at least five days is important for the person’s overall comfort.

   True   False

10. It is important for families to be educated about the possibility of the patient experiencing an energy surge, because it is a potential sign that death may occur within the next week.

   True   False