CHAPTER 48

Loss, Grieving, and Death

OBJECTIVES

After completing this chapter, you will be able to:

- Describe types and sources of losses.
- Discuss the experience of grief as a response to loss that is individually experienced and expressed.
- Outline factors affecting grief responses.
- Identify measures that facilitate the journey of grief.
- List clinical signs of impending and actual death.
- Discuss the nurse's legal responsibilities regarding client death and such issues as advance directives and do-not-resuscitate orders.
- Describe guidelines for helping clients die with dignity.
- List nursing measures for care of the body after death.
- Analyze the role of the nurse in working with families or caregivers of dying clients.

Loss, grieving, and death are experienced by everyone at some time during their life. People may suffer the loss of valued relationships through life changes, such as moving from one city to another, separation, divorce, or the death of a parent, spouse, or friend. People may grieve changing life roles as they watch grown children leave home or when they retire from their lifelong work. The loss of valued material objects through theft or natural disaster can evoke feelings of grief and loss. When people's lives are affected by civil or national strife, they may grieve the loss of valued ideals, such as safety, freedom, and democracy.

In the clinical setting, the nurse encounters clients who may be experiencing grief related to declining health, loss of a body part, terminal illness, or the impending death of self or a significant other. The nurse may also work in community settings with clients who are grieving losses related to personal crises (e.g., divorce, separation) or natural disasters (earthquakes, floods, or hurricanes). Therefore, it is important that the nurse understand the significance of loss and develop the ability to assist clients in their experiences of grief.

Nurses may interact with dying clients and their families or caregivers in a variety of settings, from the demise of a fetus, to that of an adolescent victim of an accident, to that of an elderly client who finally succumbs to a chronic illness. Nurses must recognize the various influences on the dying process—legal, ethical, religious and spiritual, biological, and personal—and be prepared to provide sensitive, skilled, and supportive care to all those affected.

Loss and Grief

Loss is an actual or potential situation in which something that is valued is changed, no longer available, or gone. People can experience the loss of body image, a significant other, a sense of well-being, a job, personal possessions, beliefs, or a sense of self. Illness and hospitalization often produce losses.

Death is a fundamental loss, both for the dying person and for those who survive. Although death is inevitable, it is an experience that each person ultimately faces alone. Yet, death, like loss, can stimulate people to grow in their understanding of themselves and others. Death can be viewed not simply as loss of life but as the dying person's final opportunity to experience life in ways that bring meaning and fulfillment.

Types and Sources of Loss

There are two general types of loss, actual and perceived. Both losses can be anticipatory. An **actual loss** can be identified by others and can arise either in response to or in anticipation of a situation. For example, a woman whose husband is dying may experience actual loss in anticipation of his death. A **perceived loss** is experienced by one person but cannot be verified by others. Psychological losses are often perceived losses in that they are not directly verifiable. For example, a woman who leaves her employment to care for her children at home may perceive a loss of independence and freedom. An **anticipatory loss** is experienced before the loss actually occurs. Loss can be viewed as situational or developmental. The loss of one's job, the death of a child, or the loss of functional ability as a result of acute illness or injury, for example, are unexpected situational losses. Losses that occur in the process of normal development—such as the departure of grown children from the home, retirement from a career, and the death of aged parents—are developmental losses that can, to some extent, be anticipated and prepared for. How individuals deal with loss is closely related to their life stages and past experiences, personal and family resources, social support systems, and their beliefs about the loss itself.

There are many sources of loss: (1) loss of an aspect of oneself—a body part, a physiological function, or a psychological attribute, (2) loss of an object external to oneself, (3) separation from an accustomed environment, and (4) loss of a loved or valued person.

Aspect of Self

The loss of an aspect of self changes a person's body image, even though the loss may not be obvious to others. A face scarred from a burn is generally obvious to people; loss of part of the stomach or loss of ability to feel emotion may not be as obvious. The degree to which these losses affect a person largely depends on the integrity of the person's body image (part of self-concept). Any change that the person perceives as negative in the way the person relates to the environment can be considered a loss of self. It should be noted that self is a culturally influenced concept, and therefore, experiences of self-loss are particular to individuals and their particular cultural and personal influences.

Such losses as divorce can have a considerable impact. A divorce may mean loss of financial security, a home, daily routines, and one's role as spouse. Therefore, even when the divorce was desired, the sense of loss can be substantial.

During old age, changes occur in physical and mental capabilities. Again the self-image is vulnerable. Old age is when people usually experience many losses: of employment, of usual activities, of independence, of health, of friends, and of family.

External Objects

Loss of external objects includes (1) loss of inanimate objects that have importance to the person, such as the loss of money or the burning down of a family's house, and (2) loss of animate objects, such as pets that provide love and companionship.

Familiar Environment

Separation from an environment and people who provide security can result in a sense of loss. The six-year-old is

likely to feel loss when first leaving the usual environment to attend school. The university student who moves away from home for the first time also experiences a sense of loss.

Loved Ones

The loss of a loved one or valued person through illness, separation, or death can, among other experiences, create suffering. In some illnesses, a person may undergo personality changes that make friends and family feel they have lost that person.

The death of a loved one is a permanent and complete loss. In primitive societies, death was considered a normal, natural event, and life was seldom long. In contemporary North American society, death is often denied. People may be uncomfortable talking about death and being around people who are dying. Sometimes, in an effort to escape the finality of death, there is a tendency to use extraordinary measures that prolong and preserve life.

The Experience of Grief

Grief has been explained as a process involving progression through a series of stages or phases requiring work or particular tasks that result in a final resolution of grief feelings (Cowles & Rodgers, 1991; Engel, 1964; Rando, 1984; Schneider, 1984; Worden, 1991). Out of this explanation, stage model theories, some of which are based on Kubler-Ross's (1969) work on death and dying, have provided one template for understanding the experience of grief. A critique of stage model theories is that although they may provide some understanding, recognition, and language for the experience of grief, they may also serve to obscure unique and individual experiences of grief (Moules, 1998). They can narrowly focus on psychological responses while overlooking social, spiritual, familial, and physical domains of the experience of grief. To understand grief as a staged experience can mistakenly invite the belief that grief occurs passively in expected sequences that disregard individual experiences and that fail to resonate with the experiences people actually undergo in grieving.

Martocchio (1985) discussed five clusters of grief, which exemplify common experiences in the grief response. These include shock and disbelief; yearning and protest; anguish, disorganization, and despair; identification in bereavement; and reorganization and restitution. Within these common experiences, however, there is no single correct way or timetable. Whether a person can successfully integrate the loss and how this is accomplished are related to that person's individual development and personal makeup. Individuals responding to the very same loss cannot be expected to follow the same pattern and schedule or reach the same outcome.

Another popularization of the experience of grief is that there is a normal grief reaction and an abnormal or unhealthy one. Grief that does not follow a predictable or expected course is often described as abnormal, complicated, pathological, unresolved, chronic, morbid, prolonged, dysfunctional, exaggerated, or disenfranchised. This pathologizing view of any divergence of expected and typical responses to loss can serve to intensify the suffering of grief, and add, in addition to the experience of loss, a sense of personal failure and incompetence (Moules, 1998).

Furthermore, socially sanctioned notions about grief invite the idea that the "work" of grief resolution is to find a way to let go of the person who is lost and to say goodbye. Alternatively, White (1989) and Moules (1998) suggested that when people lose a loved one, they continue to feel in relationship to the person, and although the relationship is necessarily changed and altered through physical absence, it continues in their emotional and spiritual life. Grief then becomes the process of learning how to live with this new and changed relationship in such a way that it offers aspects of connection and comfort, rather than pain and suffering. Grief is an unwanted visitor that arrives within the context of the experience of loss. It sweeps into every domain of one's life—biological, psychological, social, emotional, and spiritual. Grief endures in a way that shifts over time, eventually creating a mutable or changing and evolving, but, most often, a lifetime relationship with the loss. Unwanted or not, this visitor, grief, takes up residence in lives.

In nursing work with the bereaved, the challenge then is to co-evolve a way to assist people in making room for grief in their lives in ways that open space for other experiences than suffering and in inviting people to remember their lost other and say hello to a new and changed relationship (Moules, 1998).

Experiences of grief can become complicated and can have potentially devastating effects on health. Among the symptoms that can accompany grief are anxiety, depression, weight loss, difficulties in swallowing, vomiting, fatigue, headaches, dizziness, fainting, blurred vision, skin rashes, excessive sweating, menstrual disturbances, palpitations, chest pain, dyspnea, and infection. The bereaved may also experience alterations in libido, concentration, and patterns of eating, sleeping, activity, and communication.

Although bereavement can threaten health, there can be concurrent experiences within grief that can enrich the individual with new insights, values, challenges, openness, and sensitivity. For some, the pain of loss, though diminished, recurs for the rest of their lives. For some, the pain shifts into a continuing experience of remembrance, connection, and even celebration of a life well lived and loved.

A complication that can result from the intense experience of grief is a continuing experience of only sadness, loss, or even depression that is not relieved over time and is not buffered with other experiences of a return to life and joy. Another source of conflict might stem from a held belief that all people experience grief in a similar way. This belief might lead family members into expectations of each other that cannot be fulfilled and may invite a

sense of alienation, isolation, or even conflict among those people who are expected to provide comfort and connection for each other. There is some suggestion in the literature that gender differences play out in a family's experience of grief and that men and women experience, express, and have differing expectations of themselves and each other in the experience of grief and loss (Attig, 1996; DeFrain, 1991; Hughes & Page-Lieberman, 1989; Moore, Gilliss, & Martinson, 1988; Moules, 1998; Parkes, 1988; Rosen, 1990; Shapiro, 1994).

Complicating an individual's experience of grief might be ambivalence, unresolved issues, or pre-existing conflict with the lost person; a pervasive and unrelenting sense of guilt or responsibility; past experiences of loss; and the type, timing, and context of the loss (Herz Brown, 1989). Certain kinds of losses that are not synchronous with life stage expectations, such as the loss of a child as opposed to an elderly parent, can (but do not necessarily) generate more intense experiences of grief (Cowles & Rodgers, 1991; Rolland, 1991) and have the potential for more complications in the experience.

Factors Influencing the Loss and Grief Responses

A number of factors affect a person's response to a loss or death. These factors include age, significance of the loss, culture, spiritual beliefs, gender, socioeconomic status, support systems, and the cause of the loss or death. Nurses can learn general concepts about the influence of these factors on the grieving experience, but the constellation of these factors and their significance will vary from individual to individual.

Age

Age affects a person's understanding of and reaction to loss. With experience, people usually increase their understanding and acceptance of life, loss, and death.

People do not usually experience the loss of loved ones at regular intervals. As a result, preparation for these experiences is difficult. Coping with other losses in life, such as the loss of a pet, the loss of a friend, the loss of a job, and the loss of youth, can prepare people to anticipate the more severe loss of death.

Childhood Children differ from adults not only in their understanding of loss and death but also in how they are affected by the loss of others. The child's patterns progress rapidly; adult patterns of growth and development are generally stable. The loss of a parent or other significant person can threaten the child's ability to develop, and regression sometimes results. Assisting the child with the grief experience includes helping the child regain the normal continuity and pace of emotional development.

Some adults may assume that children do not have the same need as an adult to grieve the loss of others. In situations of crisis and loss, children are sometimes pushed aside or protected from the pain. They can feel afraid, abandoned, and lonely. Careful work with bereaved children is especially necessary because experiencing a loss in childhood can have serious effects later in life.

Early and Middle Adulthood As people grow, they come to experience loss as part of normal development. By middle age, for example, the loss of a parent through death seems a normal occurrence compared with the death of a younger person. Coping with the death of an aged parent has even been viewed as a necessary developmental task of the middle-aged adult.

The middle-aged adult can experience losses other than death. For example, losses resulting from impaired health or body function and losses of various role functions can be difficult for the middle-aged adult. How the middle-aged adult responds to such losses is influenced by previous experiences with loss, the person's sense of self-esteem, and the strength and availability of support.

RESEARCH NOTE

What Factors Account for Bereavement Outcome Among Spouses and Children of People Who Have Died from Cancer?

The family members of 115 adults who died from cancer in Australia were interviewed three times: six weeks, six months, and 13 months after the death. In addition to open-ended interviews, the spouse and available children also completed instruments that measured thoughts and feelings about the person who had died: depression, psychological symptoms, and social functions. The data were analyzed for correlations. The researchers found that the spouse's rating of "overall family coping" consistently correlated with grief intensity, psychological distress, depression, and social adjustment. That is, the better the family coping was viewed, the less was the grief, distress, and depression, and better adjustments were reported. The authors were able to classify families into five groups: supportive, conflict resolving, sullen, hostile, and intermediate. It is possible that the latter three groups are at greater risk for dysfunctional grieving and coping.

Implications: This research supports the importance of considering the functioning of the entire family when assessing the needs of dying clients and their significant others. It suggests that there are characteristics of families that may help identify them as being at higher risk for developing ineffective grieving and coping strategies.

Source: Kissane, D. W., Bloch, S., & McKenzie, D. P. (1997, May). Family coping and bereavement outcome. *Palliative Medicine, 11,* 191–201.

Late Adulthood Losses experienced by older adults include loss of health, loss of mobility, loss of independence, and loss of work role. Limited income and the need to change one's living accommodations can also lead to feelings of loss and grieving.

For older adults, the loss through death of a longtime mate is profound. Although individuals differ in their ability to deal with such a loss, research suggests that health problems for widows and widowers increase during the first year following the death of the spouse (Richter, 1984). Because the majority of deaths occur among elderly people and because the number of elderly people is increasing in North America, nurses will need to be especially alert to the potential problems of older grieving adults.

Significance of the Loss

The significance of a loss depends on the perceptions of the individual experiencing the loss. One person may experience a great sense of loss over a divorce; another may find it only mildly disrupting. A number of factors affect the significance of the loss:

- Value placed on the lost person, object, or function
- Degree of change required because of the loss
- The person's beliefs and values

For older people who have already encountered many losses, an anticipated loss, such as their own death, may not be viewed as a highly negative loss, and they may be apathetic about it instead of reactive. More than fearing death, some may fear loss of control or becoming a burden.

Culture

Culture influences an individual's reaction to loss. How grief is expressed is often determined by the customs of the culture. In the United States and Canada, unless an extended family structure exists, grief is handled by the nuclear family. The death of a family member in a typical nuclear North American family leaves a great void because the same few individuals fill most of the roles. In cultures where several generations and extended family members either reside in the same household or are physically close, the impact of a family member's death may be softened because the roles of the deceased are quickly filled by other relatives.

Many North Americans appear to have adopted the belief that grief is a private matter to be endured internally. Therefore, feelings tend to be repressed and may remain unidentified. People who have been socialized to "be strong" and "make the best of the situation" may not express deep feelings or personal concerns when they experience a serious loss.

Some cultural groups value social support and the expression of loss. In some groups, the expression of grief through wailing, crying, physical prostration, and other outward demonstrations are acceptable and encouraged. Other groups may frown on this demonstration as a loss of control, favouring a quieter and more stoic expression of grief. In cultural groups where strong kinship ties are maintained, physical and emotional support and assistance are provided by family members.

Spiritual Beliefs

Spiritual beliefs and practices greatly influence both a person's reaction to loss and subsequent behaviour. Most religious groups have practices related to dying, and these are often important to the client and support people. For additional information, see Chapter 13. To provide support at a time of death, nurses need to understand the client's particular beliefs and practices. A part of one's spirituality is represented in, and influences, the way one makes meaning of the experience of loss. Asking questions of a spiritual nature is within the domain of nursing practice (Moules, 1999; Wright, 1997; 1999).

Gender

As mentioned earlier, the gender roles into which many people are socialized in the United States and Canada affect their reactions at times of loss. Men are frequently expected to "be strong" and show very little emotion during grieving, whereas it is acceptable for women to show grief by crying.

Gender roles also affect the significance of body image changes to clients. A man might consider his facial scar to be "macho," but a woman might consider hers ugly. Thus, the woman, but not the man, would see it as a loss.

Socioeconomic Status

The socioeconomic status of an individual often affects the support system available at the time of a loss. A pension plan or insurance, for example, can offer a widowed or disabled person a choice of ways to deal with a loss. A person who loses a hand and can no longer carry out work-related tasks may be able to pursue vocational re-education; a wealthy person whose spouse has died may decide to take a cruise or visit relatives in Europe. Conversely, a person who is confronted with both severe loss and economic hardship may not be able to cope with either.

Support System

The people closest to the grieving individual are often the first to recognize and provide needed emotional, physical, and functional assistance. However, because many people are uncomfortable or inexperienced in dealing with losses, the usual support people may instead withdraw from the grieving individual. Also, support may be available when the loss is first recognized, but as the support people return to their usual activities, the need for ongoing support may be unmet. Sometimes, the grieving individual is unable or unready to accept support when it is offered.

Cause of Loss or Death

Individual and societal views on the cause of a loss or death may significantly influence the grief response. Some diseases are considered "clean," such as cardiovascular disorders, and engender compassion, whereas others may be viewed as repulsive and less unfortunate. A loss or death that is beyond the control of those involved may be more acceptable than one that is preventable, such as a drunk driving accident. Injuries or deaths occurring during respected activities, such as "in the line of duty," are considered honourable, whereas those occurring during illicit activities may be considered the individual's just rewards.

Assessing

Nursing assessment of the client and family experiencing a loss includes three major components: (1) nursing history, (2) assessment of personal coping resources, and (3) physical assessment. During the routine health assessment of every client, the nurse poses questions regarding previous and current losses. The nature of the loss and the meaning of such losses to the client must be explored.

If there is a current or recent loss, greater detail is needed in the assessment. Because clients do not always associate physical ailments with emotional responses, such as grief, the nurse may need to probe to identify possible loss-related stresses. If the client reports significant losses, it is important to examine how the client usually copes with loss and what resources are available to assist the client in coping. Data regarding general health status; other personal stressors; cultural and spiritual traditions, rituals, and beliefs related to loss and grieving; and the person's support network will be needed in order to determine a plan of care (see the Assessment Interview box below). In assessing the client's response to a current loss, the nurse may identify complications of grief that may be best treated by a health-care professional who is expert in assisting such clients. If the nursing assessment reveals severe physical or psychological signs and symptoms, the client should be referred to an appropriate care provider. Such complications may include clinical depression, extensive social isolation and withdrawal, severe physiological symptoms, suicidal thoughts or urges, or unrelenting and oppressive sorrow that persists for prolonged periods of time and is not balanced by any relief or joy-filled experiences.

Implementing

The skills most relevant to situations of loss and grief are attentive listening, silence, open and closed questioning,

ASSESSMENT INTERVIEW

Loss and Grieving

Previous Losses

- Have you ever lost someone or something very important to you?
- Have you or your family ever moved your home?
- What was it like for you when you first started school? Moved away from home? Got a job? Retired?
- Are you physically able to do all the things you like to do? Used to do?
- Has anyone important or close to you died?
- Do you think there will be any losses in your life in the near future?

Previous Grieving

- Tell me about (the loss). What was losing _____ like for you?
- Did you have trouble sleeping? Eating? Concentrating?
- What kinds of things did you do to make yourself feel better when something like that happened?
- Are there spiritual or cultural practices you observed when you had a loss like that?
- Whom did you turn to if you were very upset about (the loss)?
- How long did it take you to feel more like yourself again and go back to your usual activities?

Current Loss

- What have you been told about (the loss)? Is there anything else you would like to know or do not understand?
- What changes do you think this (illness, surgery, problem) will cause in your life? What do you think it will be like without (the lost object)?
- Have you ever experienced a loss like this before?
- Can you think of anything good that might come out of this?
- What kind of help do you think you will need? Who is going to be helping you with this loss?
- Are there any people or organizations in your community that might be able to help?

Current Grieving

- Are you having trouble sleeping? Eating? Concentrating? Breathing?
- Do you have any pain or other new physical problems?
- Are you taking any drugs or medications to help you cope with this loss?
- What are you doing to help you deal with this loss?

Canadian Society Notes

Fact	Implications for Nursing Practice
The Canadian Hospice Palliative Care Association (CHPCA) is the recognized national organization for leadership in palliative care. The mission of CHPCA is to promote palliative care awareness, education, and research, advocating at a national level for policy development, resource allocation, and support for caregivers.	Nurses need to be aware of the policy papers on nursing care of the dying that have been accepted by each professional association, in accordance with CHPCA standards.
Each province and territory has a provincial palliative care association that is linked to the CHPCA.	Nurses interested in palliative care may want to consider membership in these associations.
The CNA Board of Directors has awarded palliative care the designation of specialty, making it the 12th discipline to become a specialty. Over the next two years, at least 60 palliative care nurses from across the country will be involved in the development of competencies and item writing for the certification examination. It is hoped that the first palliative care nursing certification examination will be offered in 2004.	This is a tremendous achievement for palliative care nursing in Canada, and it is expected that this initiative will lead to the enhancement of palliative care for all Canadians.

paraphrasing, clarifying and reflecting feelings, and summarizing. Less helpful to clients are responses that give advice and evaluation, those that interpret and analyze, and those that give unwarranted reassurance. The offering of platitudes is often a temptation to those trying to comfort someone who is suffering a loss. Though well intended and often arising out of a loss for words, such platitudes as "It must have happened for a reason; you need to accept it," "Time heals all wounds," "Try not to think about it," "You'll get over it in time," or "Now you've got a little angel in heaven" serve only to contribute to messages that a visible grief is unhealthy and that grief is time limited (Moules & Amundson, 1997). These messages deny the right and need of the bereaved to fully experience, acknowledge, and express grief as a part of incorporating loss into their lives. What the nurse says or does is always best guided by the client and in response to the client's needs. Sometimes, a simple statement of "I am sorry for your loss," or a silent presence is what is most needed. To ensure effective communication, the nurse must make an accurate assessment of what is appropriate for the client.

Communication with grieving clients needs to be relevant to meeting clients at the point of *their* needs, not the needs of the nurse. To determine the point of a client's need, the nurse has to be willing to listen to the client's pain and suffering and not be drawn to the temptation to try to take the pain away or heal it, even if such a thing were possible.

In addition to effective communication skills, there are specific ways that a nurse can support and care for a client experiencing loss. Of these, probably the most important is that the nurse "make room for grief" (Moules, 1998). By this, we mean that the nurse accepts, facilitates, and normalizes the experience and expression of grief. This can be done in several actions and attitudes portrayed by the nurse.

- Be present, be comfortable with silence, offer touch if the person indicates that would be comforting.
- Acknowledge pain and suffering.
- Encourage talking about the loss and the loved one, but accept if clients cannot or do not wish to do so.
- Explore and respect clients' racial, cultural, religious, personal, and family values in their expression of grief.
- Explore their support system and personal resources. Who is available to be with them? Who would be most helpful right now? Who can help them take care of practical arrangements and details?
- Assist clients/families in understanding that grief is expressed differently by different people and individuals cannot be expected to adhere to others' expectations of appropriate responses to grief.
- If children are involved, encourage family members to be truthful and to allow the child to participate in the grieving activities of others.
- Though maybe not at the time of the immediate loss, support clients in exploring the meaning they have made of their loss, how they have come to understand it or live with it, and how they have come to make room for a relationship with grief in their lives.
- Provide resource and support information, such as local grief support groups or counselling.

Nursing and Grief "To enter the world of one who is grieving, we must choose to listen to the pain behind the words" (Gibbons, 1993, p. 599). To nurse clients who are suffering with loss and who are experiencing grief is not a painless practice. It is, however, a vital part of nursing. As people, we are not immune to experiences of loss and grief. These experiences are inescapable in the human condition. As such, nurses play a fundamental and important role in helping people move through these experiences with grace, support, dignity, and kindness.

Gyulay (1989) suggested that grief is a journey that is often blurred and muddy. This journey is a journey of relationship—relationship with the lost person, with oneself, with remaining people, with health-care professionals, and ultimately with grief itself. People struggle to make sense of loss and search for ways to stay in a changed relationship with the lost person. They move through the volatile, changing, unpredictable experience of grieving, sorrowing, celebrating, and change. In this movement, people come to their own methods of finding a way to make room for grief in their lives. People feel grief when a loss is significant. Grief, then, in some regards, might be seen as the act and emotion of sorrowing and celebrating the space that was made for another in love. Nurses often have the privilege of walking alongside clients for a part of this journey of relationship, and they have an obligation to do it with integrity and human compassion.

Dying and Death

The concept of death is developed over time, as the person grows, experiences various losses, and reflects on concrete and abstract concepts. In general, humans move from a childhood belief in death as a temporary state, to adulthood in which death is accepted as very real but also very frightening, and to older adulthood in which death may be viewed as more desirable than living with a poor quality of life. Table 48.1 describes some of the specific beliefs common to different age groups. The nurse's knowledge of these developmental stages helps in understanding some of the client's responses to a life-threatening situation.

Responses to Dying and Death

Understanding responses to death and dying begin with the recognition that dying individuals exist within a family system. The nurse considers the impact of the dying individual's illness on the whole family and the family's responses that affect the patient. Caring for the dying individual's family involves understanding family in the broadest sense. Family may include spouses and children, or those the dying individual defines as a "significant other" who functions in supportive ways offering emotional, spiritual, and socioeconomic companionship and, possibly, intimate bonds (Gilliss, Highly, & Roberts, 1989).

TABLE 48.1 Development of the Concept of Death

Age	Beliefs/Attitudes
Infancy to 5 years	Does not understand concept of death
	Infant's sense of separation forms basis for later understanding of loss and death
	Believes death is reversible, a temporary departure, or sleep
	Emphasizes immobility and inactivity as attributes of death
5 to 9 years	Understands that death is final
	Believes own death can be avoided
	Associates death with aggression or violence
	Believes wishes or unrelated actions can be responsible for death
9 to 12 years	Understands death as the inevitable end of life
	Begins to understand own mortality, expressed as interest in afterlife or as fear of death
12 to 18 years	Fears a lingering death
	May fantasize that death can be defied, acting out defiance through reckless behaviours (e.g., dangerous driving, substance abuse)
	Seldom thinks about death, but views it in religious and philosophic terms
	May seem to reach "adult" perception of death but be emotionally unable to accept it
	May still hold concepts from previous developmental stages
18 to 45 years	Has attitude toward death influenced by religious and cultural beliefs
45 to 65 years	Accepts own mortality
	Encounters death of parents and some peers
	Experiences peaks of death anxiety
	Death anxiety diminishes with emotional well-being
65+ years	Fears prolonged illness
	Encounters death of family members and peers
	Sees death as having multiple meanings (e.g., freedom from pain, reunion with already deceased family members)

Both the client who is dying and the family members grieve as they recognize the loss. Nurses and other health-care professionals must strive to understand the meaning of the grief experience to the dying individual and the family. Grieving may include such emotions as fear, inability to focus, hopelessness without a sense of moving beyond the death, powerlessness, losing control over one's emotions, and feelings of despair and depression. There may also be many physical symptoms, including increased pulse and respirations, dry mouth, anorexia, difficulty sleeping, and nightmares. If meaningful care is to be provided to the dying individuals and their families, the nurse must understand their beliefs and values related to the experience, how the relationships fit together, and that many factors impact their experience of dying and illness.

Caregivers, both professionals and support people, also are impacted by the impending death. The ongoing responsibilities for providing physical, economic, psychological, and social support to a dying person can create extreme stress for the provider. Often, the length of time between a terminal diagnosis and when death will occur is unknown and the people supporting the dying person become fatigued, depressed, and feel empty. There may be anger due to loss of time and resources for personal activities or attention to other people. The impending death can pose a challenge to family roles and day-to-day functioning. In this situation, the family may be unable to meet the physical, emotional, or spiritual needs of the members and may have difficulty communicating and problem solving.

Nurses who have developed a close relationship with the dying individual and family may themselves experience a sense of loss and suffer with them as they care for them in the journey of dying (Raffin, 2002). Nurses who spend many hours, even days, with the dying individual and family "do not simply care for the dying individual's physical bodies, they also tend to their spirit, gently, respectfully, and knowingly" (Moules, 2000, p. 4). The very nature of palliative care nursing is such that, every day, practitioners face some of the most fundamental and poignant issues confronting humanity (Perry, 1998). Nurses are invited to share in the intimate journey of living and dying where suffering is present. This sharing often entails a commitment of developing a meaningful relationship as a way to know and understand the dying experience. The relationship, although rewarding, often places the nurse in a vulnerable position. Nurses are affected by this position (Raffin, 2001).

People in North America are socialized to think of death as the worst occurrence in life. They, therefore, do their best to avoid thinking or talking about death—especially their own. Nurses are not immune to such attitudes. They need to take time to analyze their own feelings about death before they can effectively help others with terminal illnesses. Nurses who are unconsciously uncomfortable with dying clients tend to impede the clients' attempts to discuss dying and death in these ways:

- Changing the subject (e.g., "Let's think of something more cheerful," or "You shouldn't say things like that")
- Offering false reassurance (e.g., "You are doing very well")
- Denying what is happening (e.g., "You don't really mean that," or "You're going to live until you're a hundred")
- Being fatalistic (e.g., "Everyone dies sooner or later")
- Blocking discussion (e.g., "I don't think things are really that bad"), conveying an attitude that stops further discussion of the subject
- Being aloof and distant or avoiding the client
- "Managing" the client's care and making the client feel increasingly dependent and powerless

Caring for the dying and the bereaved is one of the nurse's most complex and challenging responsibilities, bringing into play all the skills needed for care of the whole person—mind, body, and spirit. To care for the whole person, nurses must be aware of and comfortable with their own values and beliefs about death, dying, and suffering, as this will surely impact the care they are able to give others.

Legalities Related to Death

Many legal issues surround the event of death, including a legal definition as to when a person is considered clinically dead. Few jurisdictions in Canada or the United States provide a legislative definition of the moment of death. Historically, physicians, until well into the 20th century, concurred that a person was dead when all vital signs (pulse, respiration) have ceased. In the last half of the century, medical technology has allowed physicians to sustain the lives of seriously ill individuals by means of artificial support to sustain blood circulation. As well, the advances of medical transplant technology have made possible transplantation of viable organs from deceased individuals to living recipients.

It has become apparent that the traditional medical criteria for determining the fact of death have become inadequate. In 1975, the province of Manitoba became the first (and, so far, the only) province to enact a legal definition of death. The Manitoba Vital Statistics Act suggests that "the death of a person takes place at the time at which irreversible cessation of all that person's brain function occurs." This definition conforms to the accepted medical practice. With this definition, the client still may be able to breathe but is irreversibly unconscious. People who support this definition of death believe that the cerebral cortex—which holds the capacity for thought, voluntary action, and movement—*is* the individual.

Advance Directives (Living Wills)

Any individuals receiving health care may worry, in the event of becoming incapacitated and unable to express their wishes, that they will be "hooked up to machines"

and receive treatment that they do not wish. Advance directives have been suggested as one way to address this problem. The Canadian Nurses Association (CNA, 1998b) and other sponsors produced a Joint Statement on Advance Directives for nurses' use in practice. Advance directives are "the means used to document and communicate a person's preferences regarding life-sustaining treatment in the event that they become incapable of expressing those wishes for themselves" (CNA, 1998b, p. 1). Advance directives are commonly expressed in two ways: an instruction directive, or living will, which identifies what life-sustaining treatment a person wishes in certain situations; or a proxy directive, which explains who is to make health-care decisions if the person becomes incompetent. A proxy directive is often referred to as a power of attorney for personal care (CNA, 1998b). A routine part of any admission to a hospital now includes inquiry about the client's advance directives; if they exist, they are included as part of the medical directives.

It has become necessary for nurses to be aware of the legal status of all types of advance directives in their province or territory. As outlined by the CNA (1998b), some provinces and territories only recognize proxy directives as legally binding, while others recognize both proxy and instructional directives. In addition, nurses need to become familiar with laws and documents regarding a person's competence to consent, issues regarding cardiopulmonary resuscitation (CPR), and issues at the end of life as these are closely related to advance directives (Figure 48.1).

Health-care professionals, including nurses, are responsible for ensuring that advance directives are addressed, not only as an admission duty, but rather as a part of the ongoing communication among all members providing and receiving care. A significant part of this process is to discuss and obtain a statement of the individual's personal values. This inquiry highlights the person's value system and beliefs about health, well-being, choice, and dignity. Identification of the person's values will enable the nurse to approach the hospital experience in a more holistic manner.

Euthanasia

The act of euthanasia can mean different things to different people. The word *euthanasia* comes from Greek words meaning "good death." The term is often used synonymously with the term "mercy killing," a concept that has drawn much controversy over the years. There are two forms of euthanasia: *active* and *passive*. These terms are meant to convey the difference between committing an act that causes death and omitting to take a life-sustaining act, allowing death to ensue.

The issue is an ethical one that remains unsettled. It revolves around two fundamental beliefs: the right of individuals to decide their own time and means of dying, and the equally strong argument that all measures must be tried before death is accepted as inevitable. Often, it becomes a matter of "to treat or not to treat."

A legal distinction, however, is made between acting and omitting to act. An action deliberately causing the death of another person is homicide, whereas omitting treatment when it is futile or refused is not. The withholding or withdrawing of treatments and the provision of compassionate palliative care, even when life is shortened, is considered to be good and ethical medical practice (Lowy, Sawyer, & Williams, 1993). A discussion between the physician and family members to determine when treatment should be stopped or withdrawn is ethical and common practice. Patients and family members may request that a dying individual not be subjected to resuscitative measures in the event of death, in which case the physician should write "do-not-resuscitate (DNR) order" in the patient's chart.

Individuals who argue against euthanasia base their reasoning on the principle of sanctity of life and on the traditional rules and laws prohibiting the taking of life except in situations of self-defence or war. Many are also concerned for the potential abuse of society if euthanasia were to become legal. They see the potential of this law "slipping" (slippery slope argument) to extend to such others as the chronically ill, the elderly, and the demented.

Those individuals who support euthanasia believe that there are situations in life where life is not worth living. They believe that competent individuals should be given the right to end their life when it is burdened with physical, emotional, and psychological pain that is no longer possible to eliminate. These individuals believe that sanctity of life is not an absolute principle and can be overridden out of respect for individual autonomy and for the dignity of human life.

Assisted suicide, on the other hand, means helping someone to commit suicide. It differs from euthanasia in that the person choosing to die takes the action that directly causes death, rather than having a second person commit the act. The *Criminal Code of Canada* (*CCC*) prohibits intentional killing, regardless of the person's consent or desires, and this also applies to assisted suicide. Section 14 of the *CCC* states that "no person can consent to have death inflicted on him." And, according to section 241 of the *CCC*, it is an offence to "aid a person to commit suicide, whether suicide ensues or not."

Do-Not-Resuscitate Orders

Technological advances have raised a number of troubling ethical dilemmas. These dilemmas are complicated by the following issues: health-care team conflicts, unresolved family issues, and the shortage of nurses and other resources.

Physicians may order "no code" or **"do not resuscitate" (DNR)** for clients who are in a stage of terminal, irreversible illness or expected death. A DNR order is generally written when the client or surrogate has expressed the wish for no

Personal Directive

I, _____, of _____, Alberta, do hereby:
Appoint _____, as my Agent; pursuant to the Personal Directives Act of Alberta. If (s)he predeceases me or is unavailable or unwilling to act, then I appoint _____, to be my Alternate Agent. Any Agent appointed by me shall have full authority to interpret all personal and medical decisions, and the instructions below, even if they have no bearing upon the actual situation, should I be unable to make these decisions for myself.

Primary Agent	Alternate Agent
Agent's name: _____	Agent's name: _____
Agent's address: _____	Agent's address: _____
_____	_____
Home phone: _____	Home phone: _____
Work number: _____	Work number: _____

SAMPLE

If at such a time the situation arises in which there is **no reasonable expectation of my recovery from severe physical or mental disability** to a state of meaningful interaction with loved ones, family and friends, I would like the following directions to be followed:

1. Measures of artificial life-support, in the above stated situation, that I refuse are:
    a. Cardiopulmonary resuscitation and admittance into an intensive care unit.
    b. Mechanical respiration when I cannot breathe by myself.
    c. Prolonged gastric tube or intravenous feeding when I an indefinitely unable to eat through my mouth.
    d. Antibiotic medication to treat or prevent infection.
    e. Other: _____
2. I request to live my last days at home rather than a hospital, if my family agrees.
3. If any of my tissues or organs are healthy and useful for other people I give permission for all such donation, or as specified *during my life*:
4. I do wish to have medication mercifully administered to me in order to stop suffering even though this may shorten remaining life.

Dated at _____ in the Province of Alberta, this _____ day of _____, 20_____.

_____ _____

WITNESS'S SIGNATURE **MAKER'S SIGNATURE**

Figure 48.1 Sample advanced directive appointing an agent and stating instructions

Source: The Alberta Health Ethics Network

resuscitation in the event of a respiratory or cardiac arrest. Many physicians are reluctant to write such an order if there is any conflict between the client and family members or among family members. A "supportive care only" order is written to indicate that the goal of treatment is a comfortable, dignified death and that further life-sustaining measures are not indicated.

The Canadian Association of Registered Nurses (CNA, 1995) developed a joint policy statement to provide guidance for developing policies on the appropriate use of CPR. The following guiding principles are integral to the development of the CPR policy:

1. Good health care requires open communication, discussion, and sensitivity to cultural and religious differences among caregivers, potential recipients of care, their family members, and significant others.
2. A person must be given sufficient information about the benefits, risks, and likely outcomes of all treatment options to enable him or her to make informed decisions.
3. A competent person has the right to refuse, or withdraw consent to, any clinically indicated treatment, including life-saving or life-sustaining treatment. Competence can be difficult to assess because it is not always a constant state. A person may be competent to make decisions regarding some aspects of life but not others; as well, competence can be intermittent; a person may be lucid and oriented at certain times of the day and not at others. The legal definition and assessment of competence are governed by the provinces or territories. Facilities should be aware of the laws (e.g., capacity to consent and age of consent) regarding the assessment and documentation of incompetence.
4. When a person is incompetent, treatment decisions must be based on his or her wishes, if these are known. The person's decision may be found in an advance directive or may have been communicated to the physician, other members of the health-care team, or other relevant people. In some jurisdictions, legislation specifically addresses the issue of decision making about medical treatment for incompetent people; the legislative requirements should be followed.
5. When an incompetent person's wishes are not known, treatment decisions must be based on the person's best interests, taking the following into account:
   i. The person's known values and preferences
   ii. Information received from those who are significant in the person's life and who could help in determining his or her best interests
   iii. Aspects of the person's culture and religion that would influence a treatment decision
   iv. The person's diagnosis and prognosis

   In some jurisdictions, legislation specifies who should be recognized as designated decision makers (proxies) for incompetent people; this legislation should be followed. The term "proxy" is used broadly to identify: (1) people who make a treatment decision based on the decision a person would have made for himself or herself (substitute decision maker), (2) people who help in determining what decision would be in the person's best interests, and (3) people who, under territorial/provincial legislation, are deemed an appropriate choice for making treatment decisions.
6. There is no obligation to offer a person futile or nonbeneficial treatment. Futile and nonbeneficial treatments are controversial concepts when applied to CPR. Policy makers should determine how these concepts should be interpreted in the policy on resuscitation, in light of the facility's mission, the values of the community it serves, and ethical and legal developments. For the purposes of this document and in the context of resuscitation, "futile" and "nonbeneficial" are understood as follows. In some situations, a physician can determine that a treatment is "medically" futile or nonbeneficial because it offers no reasonable hope of recovery or improvement or because the person is permanently unable to experience any benefit. In other cases, the utility and benefit of a treatment can only be determined with reference to the person's subjective judgement about his or her overall well-being. As a general rule, a person should be involved in determining futility in his or her case. In exceptional circumstances, such discussions may not be in the person's best interests. If the person is incompetent, the principles for decision making for incompetent people should be applied.

Health-care professionals should frequently revisit their policies regarding interventions such as CPR, especially in the context of a changing societal environment that recognizes the autonomy of the individual and encourages increased public discussion and participation in these issues. Decisions about CPR as an appropriate treatment option should be clearly identified on a patient's record to make sure that all the involved health-care professionals are aware of these decisions (CNA, 1995).

Death-Related Religious and Cultural Practices

Various cultural and religious traditions and practices associated with death, dying, and the grieving process help people cope with these experiences. Nurses are often present through the dying process and at the moment of death. Knowledge of the client's religious and cultural heritage helps nurses provide individualized care to clients and their families, even though they may not participate in the rituals associated with death.

Dying in solitude is generally unacceptable in most cultures. In many cultures, people prefer a peaceful death at home rather than in the hospital. Members of some ethnic groups may request that health-care professionals not reveal the prognosis to dying clients. They believe the person's last days should be free of worry and pain. People in other cultures prefer that a family member (preferably a male in some cultures) be told the diagnosis so that the client can be tactfully informed by a family member in gradual stages or not be told at all. Nurses also need to determine whom to call, and when, as the impending death draws near.

Beliefs and attitudes about death, its cause, and the soul also vary among cultures. Unnatural deaths, or "bad deaths," are sometimes distinguished from "good deaths." Also, the death of a person who has behaved well in life may be considered less threatening based on the belief that the person will be reincarnated into a good life.

Beliefs about preparation of the body, autopsy, organ donation, cremation, and prolonging life are closely allied to the person's religion. *Autopsy*, for example, may be prohibited, opposed, or discouraged by Eastern Orthodox religions, Muslims, Jehovah's Witnesses, and Orthodox Jews. Some religions prohibit the removal of body parts and dictate that all body parts be given appropriate burial. *Organ donation* is prohibited by Jehovah's Witnesses and Muslims, whereas Buddhists in North America consider it an act of mercy and encourage it. *Cremation* is discouraged, opposed, or prohibited by the Mormon, Eastern Orthodox, Islamic, and Jewish faiths. Hindus, in contrast, prefer cremation and cast the ashes in a holy river. *Prolongation of life* is generally encouraged; however, some religions, such as Christian Science, are unlikely to use medical means to prolong life, and the Jewish faith generally opposes prolonging life after irreversible brain damage. In hopeless illness, Buddhists may permit euthanasia.

Nurses also need to be knowledgeable about the client's death-related rituals, such as last rites and administration of Holy Communion, chanting at the bedside, and other rituals, such as special procedures for washing, dressing, positioning, and shrouding the dead. For example, certain cultures may wish to practise their native customs in which family members of the same sex wash and prepare the body for burial and cremation. Muslims also customarily turn the body toward Mecca. Nurses need to ask family members about their preference and verify who will carry out these activities. Burial clothes and other cultural or religious items are often important symbols for the funeral. For example, faithful Mormons are often dressed in their "temple clothes." Some Native Americans may be dressed in elaborate apparel and jewellery and wrapped in new blankets with money. The nurse must ensure that any ritual items present in the health-care agency be given to the family or to the funeral home.

Assessment During the Transition of Active Dying

Through the process of coming to know the dying individual and family's beliefs, desires, and needs in the journey of dying, the nurse through continued conversation/assessment collects a complete patient/family history which includes physical, emotional, social, and spiritual dimensions. In this relationship, the nurse becomes aware of the living/dying transitions that the dying individual and family experience. Knowing the dying individual and family allows the nurse to respond in a way that best supports their state of awareness, beliefs, and values about the dying journey. Glaser and Strauss (1965) described four types of awareness of impending death: closed awareness, suspected awareness, mutual pretense, and open awareness.

In **closed awareness,** the dying individual, and perhaps the family, is unaware of impending death. They may not completely understand why the client is ill, and they believe the client will recover. The physician may believe it is best not to communicate a diagnosis or prognosis to the dying individual. Nurses are confronted with an ethical situation that they must work through. While the intention is to protect the dying individual, difficulties result for the family and the nurse. Families and patients do not have the opportunity to communicate openly and to freely express their feelings, share the burden of grief, and plan realistically for the future. Nurses in this situation express a feeling of ethical burden as they are not able to communicate openly and freely and potentially do not uphold moral values of veracity, or dignity.

In **suspected awareness,** dying individuals do not remain unaware for long. Their deteriorating state of health, changes in physical appearance, and altered behaviours of family members and health-care professionals lead to suspected awareness. The dying individual senses that the information given may not be the truth. Feeling like their trust has been undermined, they choose not to voice what they are sensing, and thus, communication becomes even more difficult.

With **mutual pretense,** the dying individual, family, and health-care personnel know that the prognosis is terminal but do not talk about it and make an effort not to raise the subject. Sometimes, the dying individual refrains from discussing death to protect the family from distress. The client may also sense discomfort on the part of health-care personnel and, therefore, does not bring up the subject. Mutual pretense permits the client a degree of privacy and dignity, but it places a heavy burden on the dying person who then has no one in whom to confide fears.

With **open awareness,** the dying individual and people around know about the impending death and feel comfortable discussing it, even though it is difficult. This awareness provides the client an opportunity to finalize affairs and even participate in planning funeral arrangements.

Not all people can handle open awareness. Some believe that terminal clients acquire knowledge of their condition

Signs of Impending Clinical Death

Loss of Muscle Tone

- Relaxation of the facial muscles (e.g., the jaw may sag)
- Difficulty speaking
- Difficulty swallowing and gradual loss of the gag reflex
- Decreased activity of the gastrointestinal tract, with subsequent nausea, accumulation of flatus, abdominal distention, and retention of feces, especially if narcotics or tranquilizers are being administered
- Possible urinary and rectal incontinence due to decreased sphincter control
- Diminished body movement

Slowing of the Circulation

- Diminished sensation
- Mottling and cyanosis of the extremities
- Cold skin, first in the feet and later in the hands, ears, and nose (the client, however, may feel warm because of elevated body temperature)
- Decelerated and weaker pulse
- Decreased blood pressure

Changes in Respirations

- Rapid, shallow, irregular, or abnormally slow respirations; Cheyne-Stokes respirations; noisy breathing, referred to as the *death rattle*, due to collection of mucus in the throat; mouth breathing, which leads to dry oral mucous membranes

Sensory Impairment

- Blurred vision
- Impaired sense of taste and smell

even if they are not directly informed. Others believe that many clients remain unaware of their condition until the end. It is difficult, however, to distinguish what clients know from what they are willing to accept.

Nursing care and support for the dying client and family include making an accurate assessment of the physiological signs of approaching death. In addition to signs related to the client's specific disease, certain other physical signs are indicative of impending death. The four main characteristic changes are loss of muscle tone, slowing of the circulation, changes in respirations, and sensory impairment. See the box above for indications of impending clinical death.

Various consciousness levels occur just before death. Some clients are alert, whereas others are drowsy, stuporous, or comatose. Hearing is thought to be the last sense that is lost.

ASSESSMENT GUIDELINES

The Dying Individual

Ask the spouse, partner, or significant others:

- Have you ever been close to someone who was dying?
- What have you been told about what may happen when death occurs?
- Do you have questions about what may happen at the time of death?
- Do you have questions about how we are caring for _____ during these last days?
- How do you think you would like to say goodbye?
- How are you taking care of yourself during these times?
- Who can you turn to for help at this time?
- Is there anyone you would like us to contact now or when death occurs?

As death approaches, the nurse assists the family and other significant people to prepare themselves. Depending, in part, upon knowledge of the person's state of awareness, the nurse asks questions that help identify ways the nurse can provide support during the period before and after death. In particular, the nurse needs to know what the family expects to happen when the person dies so accurate information can be given at the appropriate depth. See the box above for sample interview questions. When the family members know what to expect, they are better able to support the dying person and others who are grieving. In addition, they may be able to make certain decisions about events surrounding the death, such as whether they will want to view the body after death.

Planning a Peaceful Death Major desires of dying individuals are (1) maintaining physiological and psychological comfort, and (2) achieving a dignified and peaceful death, which includes maintaining personal control and accepting declining health status. When planning care with these clients, the Dying Person's Bill of Rights can be a useful guide (see the next box).

Examples of specific desired outcomes, although established in the planning phase, are provided in Table 48.4 entitled "Goals in Fostering a Peaceful Death" later in this chapter.

Examples of nursing interventions for the dying individual include the following:

- Helping individuals die with dignity
- Meeting physiological needs
- Providing spiritual support
- Supporting the family
- Providing postmortem care

The Dying Person's Bill of Rights

I have the right to be treated as a living human being until I die.

I have the right to maintain a sense of hopefulness, however changing its focus may be.

I have the right to be cared for by those who can maintain a sense of hopefulness, however changing this might be.

I have the right to express my feelings and emotions about my approaching death in my own way.

I have the right to participate in decisions concerning my care.

I have the right to expect continuing medical and nursing attention even though "cure" goals must be changed to "comfort" goals.

I have the right not to die alone.

I have the right to be free from pain.

I have the right to have my questions answered honestly.

I have the right not to be deceived.

I have the right to have help from and for my family in accepting my death.

I have the right to die in peace and dignity.

I have the right to retain my individuality and not be judged for my decisions which may be contrary to beliefs of others.

I have the right to discuss and enlarge my religious and/or spiritual experiences, whatever these may mean to others.

I have the right to expect that the sanctity of the human body will be respected after death.

I have the right to be cared for by caring, sensitive, knowledgeable people who will attempt to understand my needs and will be able to gain some satisfaction in helping me face my death.

Source: Barbus, A. J. (1975, January). The dying person's bill of rights, © 1975, American Journal of Nursing Company. Reprinted with permission from the *American Journal of Nursing, 75*, 99.

Planning for Home Care

A major factor in determining whether a person will die in a health-care facility or at home is the availability of willing and able caregivers. If the dying person wishes to be at home, and family or others can provide care to maintain symptom control, the nurse should facilitate a referral to hospice services. Hospice staff and nurses will then conduct a full assessment of the home and care providers' skills.

The major nursing responsibility for clients who are dying is to assist the individual to a peaceful death. More specific responsibilities are the following:

- To provide relief from loneliness, fear, and depression
- To maintain the client's sense of security, self-confidence, dignity, and self-worth
- To maintain hope
- To help the client accept losses
- To provide physical comfort

People facing death need help facing the fact that they will have to depend on others. Some dying clients require only minimal care and can be cared for at home; others need continuous attention and the services of a hospital and its staff. People need help, well in advance of death, in planning for the period of dependence. They need to consider what will happen and how and where they would like to die.

Helping Individuals Die with Dignity

Dignity may be defined as the ability to function as a significant and integrated person. True dignity comes from within. Generally, dependence on others and loss of control over oneself and interactions with the environment are associated with loss of dignity. Nurses need to ensure that the client is treated with dignity, that is, with honour and respect. Dying clients often feel they have lost control over their lives and over life itself. By introducing options available to the client and significant others, nurses can restore and support feelings of control. Some choices that individuals can make are the location of care (e.g., hospital, home, or hospice), times of appointments with health-care professionals, activity schedule, use of health-care resources, and times of visits from relatives and friends.

Most clients interviewed about dying indicate that they want to be able to manage the events preceding death so they can die peacefully. Nurses can help individuals to find meaning and completeness and to determine their own physical, psychological, and social priorities. Dying people often strive for self-fulfillment more than for self-preservation, and they need to find meaning in continuing to live while suffering. Part of the nurse's challenge, then, is to help maintain, day to day, the client's will and hope.

Often, nurses have difficulty discussing death with clients who are dying. Although it is natural for people to be uncomfortable discussing death, steps can be taken to make such discussions easier for both the nurse and the client. Callanan (1994) lists the following strategies:

- Identify personal feelings about death and how they may influence interactions with clients. Acknowledge personal fears about death, and discuss them with a friend or colleague.
- Focus on the client's needs. The client's fears and beliefs may be different from the nurse's. It is important that the nurse avoid imposing personal fears and beliefs on the client or family.

- Understand the client and how the client copes. Talk to the client or the family about how the client usually copes with stress. Clients will use their usual coping strategies for dealing with impending death. For example, if they are usually quiet and reflective, they will become quieter and more withdrawn when facing terminal illness.
- Establish a communication relationship that shows concern for and commitment to the client. Communication strategies that let the client know you are available to talk about death include the following:
  a. Describe what you see, for example, "You seem sad. Would you like to talk about what's happening to you?"
  b. Clarify your concern, for example, "I'd like to know better how you feel and how I may help you."
  c. Acknowledge the client's struggle, for example, "It must be difficult to feel so uncomfortable. I care about you and would like to help you be more comfortable."
  d. Provide a caring touch. Holding the client's hand or offering a comforting massage can encourage the client to verbalize feelings.
- Determine what the client knows about the illness and prognosis.
- Respond with honesty and directness to the client's questions about death.
- Make time to be available to the client to provide support, listen, and respond.

Hospice/Palliative Care

Hospice or palliative care has emerged as a specialized field only within the past 30 years (Billings, 1998). The term *hospice* has sometimes been used interchangeably with the term *palliative care*, but more recently, the terms have come to have different meanings (Vachon, 2001). In the United Kingdom, a hospice is a building where dying persons are cared for, but many of these individuals are discharged home and followed up by home care programs. In the United States, the term refers to a specific programmatic model for delivering palliative care. In Canada, hospices are often community-based, volunteer-driven programs providing care in the home or in a free-standing hospice (Vachon, 2001).

Regardless of location or type of program, hospice care is based on the principles of providing care to improve the dying individual's quality of life, rather than aim for cure. The care is patient and family centred, focusing on needs and concerns that are most important to them. A hallmark of palliative/hospice care since Cicely Saunders founded the modern hospice movement has been the combination of scientific rigour with personal concern. By opening the St. Christopher's Hospice, Saunders developed an education program for palliative care which embraced three broad areas: (1) the science and techniques of pain management and symptom control, (2) knowledge of psychosocial, social, and spiritual aspects of dying and grieving; (3) self-knowledge on the part of caregivers, especially related to personal beliefs about death and loss (Barnard, Boston, Towers, & Lambrinidou, 2000). Hospice/palliative care is always provided by a multidisciplinary team of primarily physicians, nurses, social workers, and chaplains.

Meeting Physiological Needs of the Dying Individual

The physiological needs of people who are dying are related to a slowing of body processes and to homeostatic imbalances. Interventions include providing personal hygiene measures; controlling pain; relieving respiratory difficulties; assisting with movement, nutrition, hydration, and elimination; and providing measures related to sensory changes. See also Table 48.2.

Figure 48.2 The patient/family are the "unit of care" in hospice palliative care

Figure 48.3 Hospice care is based on the principles of providing care to improve the dying individual's quality of life

TABLE 48.2 Physiological Needs of Dying Persons

Problem	Nursing Interventions
Ineffective airway clearance	30° Fowler's position: conscious clients
	Lateral, throat suctioning: conscious clients
	Sims', 30° lateral, and lateral position: unconscious clients
Self-care deficit: bathing/hygiene	Frequent baths and linen changes, if diaphoretic
	Mouth care, as needed, for dry mouth
Impaired physical mobility	Assist client out of bed periodically, if client is able
	Regularly change bedridden client's position
	Support client's position with pillows, blanket rolls, or towels, as needed
	Elevate client's legs when sitting up to prevent pooling of blood
Imbalanced nutrition: less than body requirements	Antiemetics or small amount of alcoholic beverage to stimulate appetite
	Encourage liquid foods, as tolerated
Constipation	Dietary fibre, as tolerated
	Laxatives, as needed, to prevent constipation
Impaired urinary elimination	Skin care in response to incontinence of urine or feces
	Bedpan, urinal, or commode chair within easy reach
	Call light within reach for assistance onto bedpan or commode
	Absorbent pads placed under incontinent client; linen changed as often as needed
	Catheterization, if necessary
	Keep room as clean and odour free as possible
Disturbed sensory perception: visual, tactile	Clients prefer a well-lit room
	Hearing is *not* diminished; speak clearly and do not whisper
	Touch is diminished, but client will feel pressure of touch

Sensory Perceptual Needs

Changes in the level of consciousness may be the first symptom, occurring over a period of weeks or days. Changes may include cloudiness of thought, drowsiness, stupor or unresponsiveness, coma, and, in some individuals, confusion or agitation. Consciousness is an integral aspect of being human; the ability to relate to others and the environment allows the individual an important sense of control. Even though individuals may have mentally accepted the fact that they are dying, the actual process of losing consciousness and the awareness of death may be a frightening experience. The fatigue and exhaustion of illness may prompt a wish of "falling asleep and not waking up." Others may struggle to continue to live and, thus, be very restless and unsettled until death. As the client's body slows down, the nurse must use the knowledge of normal physiological changes to prepare the client for death and lessen anxiety (see Table 48.3).

Pain Management

One of the greatest fears of dying individuals is that they will experience intense unbearable pain. In a study of cancer patients near the end of life, pain occurred in 54 percent and 34 percent at four weeks and one week prior to death, respectively (Coyle, Adelhardt, & Foley, 1990). In other studies of patients admitted to palliative care units, pain is often the dominant symptom along with fatigue and dyspnea (Jenkins, Taube, Ken, Hanson, & Bruera, 1998; Ng & von Gunten, 1998). Pain control is essential because pain alters sleep, appetite, mobility, energy levels, and psychological functioning. Barriers to good pain relief are numerous and pervasive. Often, due to lack of education, misconceptions, and attitudinal issues, these barriers prevent many individuals from receiving adequate pain relief (Parageon & Hailey, 1999).

Most nurses are educated in the observation and assessment of acute pain, which is very different from chronic pain. The dramatic signs and symptoms of acute pain warrant fast and immediate action. Outward signs of chronic pain are not as obvious and, therefore, may go untreated. Lack of expression does not mean lack of pain. Comprehensive assessment of pain is imperative. This must be conducted initially, regularly throughout treatment, and during any changes in the patient's experience of pain. Performing an

TABLE 48.3 State of Consciousness in Dying Patients

A. Consciousness: To be fully conscious is to be aware of one's self and the surrounding environment. There are two aspects:

1. *Content.* The sum of mental processes, including the ability to discriminate among both the sensory inputs and the internal cognitive aspects.

2. *Arousal.* A state of wakefulness or alertness to external and internal processes.

B. Clouding of Consciousness: Defined as a reduced state of wakefulness or awareness.

1. *Mild Clouding.* For the terminal patient, fatigue and periods of drowsiness are not uncommon. After a period of rest, the patient remains fully conscious. Several other features may not be observed or appreciated by caregivers in the early part of this phase. These features include the following:

- Excitability and irritability, which alternate with drowsiness
- Startled by minor stimuli
- Easily distracted
- Misjudges sensory perception, especially visual
- Cannot think clearly or quickly

These features may be intermittent and mistaken for anxiety.

2. *Advanced or subacute confusional state.* In this phase, the intensity and persistence of the symptoms is increased. The patient is "confused."

- Stimuli are more consistently misinterpreted.
- Attention span is shortened.
- The patient is bewildered and has difficulty following commands.
- There is some disorientation to time and sometimes to place and person.
- Memory is faulty.
- Drowsiness is often prominent (may alternate with nighttime agitation).

3. *Delirium.* The next "lower" level of consciousness is delirium. Although defined and used here in the classical sense, the term is not consistently used in all practice settings where care of the dying is provided. The word has a connotation of being "crazy" and is inappropriate in working with dying patients. The next phases are referred to as lower levels of consciousness.

Symptoms at this level include the following:

- Intensified disorientation
- Misinterpretation of stimuli; often visual hallucinations
- Lucid periods that often alternate with delirium
- Delusions
- Loud, talkative, offensive, suspicious, or agitated behaviour

4. *Stupor.* Stupor is defined as a state in which the patient is unresponsive but briefly arousable, only during vigorous and repeated stimuli, and then immediately drifts back to unresponsiveness.

In this stage, the patient may moan or be briefly restless when being turned or when given skin care. Staff need to ascertain whether this "moaning" is due to insufficient pain control or simply being partially roused from a deeper level.

This is not a "withdrawn" state in which the patient, lying in a fetal position, is conscious but does not respond to people. In this type of case, the patient will initially appear to be in a stupor but is, in fact, conscious and just not responding to family or caregivers. Management (and prognosis) of this state is very different from that for the truly stuporous patient.

5. *Coma.* This is the true comatose state, defined as complete unarousable unresponsiveness or "the absence of any psychologically understandable response to external stimuli or inner need."

This is exemplified in a patient who is breathing on his own but is totally unarousable by any physical stimulus, such as pinching, heat or cold, and yelling or sudden noise. There is no intake by the patient.

Source: Victoria Hospice Society, 1998.

individualized pain assessment is the first step to ensuring baseline data and continued treatment resulting in an improved quality of life for the dying individual.

Once the individual's pain has been assessed, a choice of analgesic medication to control the pain is selected (opioid or nonopioid analgesics). The World Health Organization (1990) recommends the use of an analgesic ladder to assist with analgesic selection. With chronic pain, analgesics are generally most effective if administered regularly (or around the clock) rather than on an as-needed basis. Frequently, when patients receive a regular dose of medication, pain may "break through" and require additional doses to keep it under control. Opioid or controlled narcotic substances are used for managing moderate to severe pain. For primarily historical reasons, morphine is the strong opioid of choice. Nonopioid medications are commonly used to ease pain and lower fever. They are generally used for managing mild to moderate pain. Medications for pain management are not limited to analgesics. Medications can include corticosteroids, antidepressants, anticonvulsants, and anxiolytics, determined by the type of pain assessed. Other than med-

ications for the control of pain, there are therapeutic comfort measures performed by the nurse, such as helping the patient relax, providing music, giving warm soothing baths or a massage, providing distraction, and using peripheral nerve stimulators. (See Chapter 45.) The presence of the nurse to ensure support, conversation, and genuine concern is most important and assists in the process of reducing pain and promoting comfort.

Breathing Needs

Shortness of breath (dyspnea) is an uncomfortable awareness of breathing. Like pain, dyspnea is a subjective sensation involving both the perception of breathlessness and the individual's reaction to it. The prevalence of dyspnea varies according to the disease. Approximately 50 percent of the general outpatient cancer population experiences some breathlessness, with this number rising to 45 to 70 percent in the terminal phase of the disease (Dudgeon, Kristjanson, Sloan, & Lertzman, 1999; Fainsinger, MacEachern, Hanson, Miller, & Bruera, 1991).

Dyspnea, like pain, is multidimensional in nature, with not only physical symptoms but also affective components which are shaped by an individual's past experience with dyspnea. Dyspnea, like pain, may not always be evident to the observer. The nurse should inquire specifically about shortness of breath. Occasionally, dying individuals may have physical signs of tachypnea and appear to be in distress; however, they may not feel dyspneic or distressed. The opposite may also occur where individuals who are not tachypneic or in apparent respiratory distress may describe feeling very short of breath. The extent of breathlessness experienced by a patient may or may not be related to the oxygen saturation level. Therefore, the patient's own assessment of level of dyspnea may be a more reliable indicator than the oxygen saturation level. Dyspnea is, thus, a symptom that needs to be reported by the dying individual.

The nurse provides many comfort measures to help relieve, decrease the perception of, and comfort the experience of dyspnea, including (1) the administration of medications, such as opioids, bronchodilators, and diuretics, (2) creating a therapeutic environment where the individual engages in distraction therapy, relaxation exercises, is allowed to rest, or be with family, (3) assisting the individual to a position that makes breathing easier (usually a high sitting position is best), and offering a fan to reduce the perception of breathlessness, (4) offering fluids and using a humidifier to loosen mucus so coughing is easier, and (5) administering oxygen therapy by mask or nasal cannula. If hypoxic, maintain oxygen saturation above 90 percent. The nurse has to be cautious in offering oxygen to a patient with chronic obstructive pulmonary disease (COPD); in these individuals, oxygen saturation should be kept around 90 percent or as ordered by the physician (Pereira & Bruera, 1999). It is important that the nurse offer these interventions early in the experience of dyspnea to reduce anxiety and improve quality of life.

The importance of teaching the dying individual and family cannot be overlooked. Strategies to relieve the acute experience of dyspnea include (1) positioning and structured relaxation techniques, (2) signs and symptoms of an impending exacerbation, (3) techniques to conserve energy and prioritize activities, and (4) ways to maximize the effectiveness of taking medications, such as using a spacer with inhaled drugs and taking an additional dose of the medications prior to activity, as ordered.

Acknowledging and Strengthening Spirituality

Spirituality is an inherent, integrating, and, often, extremely valued dimension of the journey of dying for individuals and their families. Spiritual distress or "soul pain" is a common experience in those who are dying and, sometimes, an experience that is not addressed or understood. The experiences are complex, varied, and individual, and if left unaddressed, they may stifle the opportunity for growth, heighten the loss of a sense of meaning and purpose, and contribute to poorly controlled symptoms (Raffin, 2002).

Often, the experience of suffering prompts people, whether or not they see themselves to be religious, to ask deeply spiritual questions and turn to God or a spiritual guide for solace. Even in the case of those who are avowedly religious, suffering can lead to questioning of fundamental beliefs (Anderson, 1989). To appreciate individual responses to suffering, it is imperative that the nurse attempt to understand the religious/spiritual views of the sufferer.

The compassionate nurse, in a relationship with dying individuals who are suffering, creates space and time in which the nurse considers the dying individual's expression of spirituality. The nurse embraces the experience of the dying individual's loneliness, anxiety, the need to incorporate a transcendent dimension into one's life (faith or religion), the need for relatedness, and/or the need to search for meaning in suffering (Raffin, 2002). For many nurses, this begins with a self-exploration of spirituality that may or may not reveal an inner strength related to a belief in and a sense of interconnectedness with a greater being. Such an exploration brings the nurse face to face with existential questions, such as the inevitability and finality of death. Personal exploration often leads to a spiritual search for faith and/or other religious resources or questions (Raffin, 2002).

Spirituality delves into the nature of humanity and the deep mysteries of life. Spirituality, as related to nurses in a relationship with dying individuals, encompasses values, meaning, and purpose; turning inward to the human traits of honesty, love, caring, wisdom, and compassion; helping others to search for a higher authority, guiding spirit, or transcendence that is mystical; and helping create healing of body, mind, and spirit that may or may not

involve organized religion. Nurses, in helping others find their expression of spirituality, allow for an open interpretation of what the individual considers to be divine or a transcendent Other.

Nurses have a responsibility to not impose their own religious or spiritual beliefs on a client but to respond to the client in relation to the client's own background and needs. Openness and honesty are most important in helping the client articulate needs and in developing a sense of caring and trust.

Specific interventions may include facilitating expressions of feeling, prayer, meditation, reading, and discussion with appropriate clergy or a spiritual adviser. It is important for nurses to establish an effective interdisciplinary relationship with spiritual support specialists. For a further discussion of spiritual issues, see Chapter 13. Death-related beliefs and practices of selected groups are discussed earlier in this chapter.

Caring for the Family

At no time is the family more important than during the times of death and dying. Nurses have an obligation to not only include the family in the care of the client but also to honour their wisdom, their beliefs, their wishes, and their needs. In this act of honouring, it is important to meet families at the point of their needs, rather than have set and unbending expectations of how family members will react to and involve themselves during the profound and difficult experience of watching a loved one die.

The most important thing a nurse can do to care for family members is to acknowledge them and include them. If the nurse shifts her thinking from considering the dying individual as the client to accepting the entire family as the client, then care becomes focused on the very significant event that is happening not just to the person but to the entire family system. Acknowledging family members includes consulting the family in terms of care of client and honouring their wisdom and knowledge of the dying individual. It involves a collaborative evolution of ways in which the family needs to be involved and ways in which they prefer the nurse to assume care. For example, some family members want to be involved in physical care, whereas other family members are more comfortable with the nurse assuming these caring practices. It is important, in asking the family members' preferences, to not imply that the nurse has an expectation that they assume these acts, but rather that the nurse respects the members' level of comfort. One way to approach this delicate establishment of roles and involvement would be to say to the family: "Sometimes family members like to be involved in the physical care of their ill members, other times they prefer the nurse to assume these things. What would be most comfortable for you in this area?" At times, family members want other kinds of involvement, rather than physical care, but are unsure of how to offer this. The nurse can help guide family members in knowing that it may be soothing to dying individuals to speak to them, read to them, hold their hands, or simply be present.

A part of what a nurse offers a family is a caring and compassionate presence. Compassion is defined as "suffering with." Though the nurse is not suffering as the family is, the nurse has in some ways entered the world of the family's suffering. "In entering the world of the one who is suffering, we do have to open space to where we listen to the pain, where we see, touch, and feel the pain" (Moules, 1999). Nurses create a context where family members feel as though they can be open about their pain, suffering, and grief. Nurses can offer information about the process of what is occurring and thereby walk alongside the family in understanding this experience.

When the individual dies, family members should be invited to spend time with the body as this important ritual can serve as a significant event in making room for grief and grieving. Some people ask for mementos, such as locks of hair or other bodily reminders. Children should not be discouraged from being involved in this important ritual of viewing the body, and at times, nurses may offer encouragement or even permission to families that it is appropriate to include children. Family members may have specific desires to participate in some care of the body, as in the case of a mother who asked to bathe her child one last time and dress him in special clothes. The nurse, in this instance, helped prepare clean towels and a basin for the mother, showing sensitivity in commenting that the water needed to be warmer, and then returning with warm water. The mother later reported that this simple act of kindness was of great comfort to her. In a health-care system that is often pushed for beds, the nurse may, at times, need to act as an advocate for families to ensure that they have all the time they need to spend with the body to begin saying goodbye to the physical presence of this person in their lives.

Postmortem Care

Rigor mortis is the stiffening of the body that occurs abut two to four hours after death. It results from a lack of adenosine triphosphate (ATP), which is not synthesized because of a lack of glycogen in the body. ATP is necessary for muscle fibre relaxation. Its lack causes the muscles to contract, which, in turn, immobilizes the joints. Rigor mortis starts in the involuntary muscles (heart, bladder, and so on), then progresses to the head, neck, and trunk, and finally reaches the extremities.

Because the deceased person's family often wants to view the body and because it is important that the deceased appear natural and comfortable, nurses need to position the body, place dentures in the mouth, and close the eyes

and mouth *before* rigor mortis sets in. Rigor mortis usually leaves the body about 96 hours after death.

Algor mortis is the gradual decrease of the body's temperature after death. When blood circulation terminates and the hypothalamus ceases to function, body temperature falls about 1°C per hour until it reaches room temperature. Simultaneously, the skin loses its elasticity and can easily be broken when removing dressings and adhesive tape.

After blood circulation has ceased, the red blood cells break down, releasing hemoglobin, which discolours the surrounding tissues. This discolouration, referred to as **livor mortis,** appears in the lowermost or dependent areas of the body.

Tissues after death become soft and eventually liquefied by bacterial fermentation. The hotter the temperature, the more rapid the change. Therefore, bodies are often stored in cool places to delay this process. Embalming prevents the process through injection of chemicals into the body to destroy the bacteria.

Nursing personnel may be responsible for care of a body after death. Postmortem care should be carried out according to the policy of the hospital or agency. Because care of the body may be influenced by religious law, the nurse should check the client's religion and make every attempt to comply. If the deceased's family or friends wish to view the body, it is important to make the environment as clean and pleasant as possible and to make the body appear natural and comfortable. All equipment, soiled linen, and supplies should be removed from the bedside. Some agencies require that all tubes in the body remain in place; in other agencies, tubes may be cut to within 2.5 cm of the skin and taped in place; in others, all tubes may be removed. Legal issues surrounding the death (e.g., coroner's case) may necessitate that all tubes remain in place.

Normally, the body is placed in a supine position with the arms either at the sides, palms down, or across the abdomen. One pillow is placed under the head and shoulders to prevent blood from discolouring the face by settling in it. The eyelids are closed and held in place for a few seconds so they remain closed. Dentures are usually inserted to help give the face a natural appearance. The mouth is then closed.

Soiled areas of the body are washed; however, a complete bath is not necessary because the body will be washed by the **mortician** (also referred to as an **undertaker**), a person trained in care of the dead. Absorbent pads are placed under the buttocks to take up any feces and urine released because of relaxation of the sphincter muscles. A clean gown is placed on the client, and the hair is brushed and combed. The top bed linens are adjusted neatly to cover the client to the shoulders. Soft lighting and chairs are provided for the family.

In the hospital, after the body has been viewed by the family, additional identification tags are applied. The body is wrapped in a **shroud,** a large piece of plastic or cotton material used to enclose a body after death. Identification is then applied to the outside of the shroud. The body is taken to the morgue if arrangements have not been made to have a mortician pick it up from the client's room.

FOCUS ON CRITICAL THINKING

Mrs. Govinda was a 75-year-old female who was admitted to the hospital after repeated episodes of pneumonia. Despite aggressive antibiotic therapy, Mrs. Govinda's condition rapidly deteriorated and she died unexpectedly one week after being admitted to the hospital. Mrs. Govinda's oldest son, who lived nearby and frequently cared for his mother, made arrangements for the funeral and visited with relatives. He misses his mother and cries occasionally, but he managed to return to work the following week. The youngest son had difficulty attending the funeral, has been unable to sleep or eat, cannot concentrate at work, and cannot believe that his mother is dead. The middle son did not weep at the funeral and had little to say to his brothers or other relatives. He returned home to another province and has remained distant. He is back at work but feels very fatigued and apathetic.

1. From the data provided, describe the phase of bereavement being experienced by each of the three sons.
2. What factors may have affected how each of the brothers reacted to the death of their mother?
3. What cues, other than physical signs, might have indicated that Mrs. Govinda was dying even though her death was unexpected?
4. What is the primary factor to consider when trying to make the decision to administer or withhold pain medication when a client is dying?
5. Explore your own feelings about death, and consider how those feelings may affect the care you provide to the dying client.

See Appendix A for answers to these questions.

Evaluating the Process of Care To evaluate the achievement of client goals, the nurse collects data in accordance with the desired outcomes established in the planning phase. Evaluation activities may include the following:

- Listening to the client's reports of feeling in control of the environment surrounding death, such as control over pain relief, visitation of family and support people, or treatment plans
- Observing the client's relationship with significant others
- Listening to the client's thoughts and feelings related to hopelessness or powerlessness

Examples of desired outcomes are shown in Table 48.4.

TABLE 48.4 Goals in Fostering a Peaceful Death

Goal	Examples of Desired Outcomes
Maintain personal control over present situation	Identifies areas of personal control
	Participates in self-care activities in accordance with health status
	Makes choices related to care and treatment
	Expresses sense of control over the present situation
Maintain comfort	Maintains physiological comfort
	Maintains psychological comfort
	Skin and oral tissues hydrated
	Absence of constipation or urinary retention
	Absence of restlessness
Accept declining health status	Shares values and personal meaning of life
	Verbalizes acceptance of situation
	Accepts limitations and seeks help, as needed

CHAPTER HIGHLIGHTS

- Nurses help clients deal with all kinds of losses, including loss of body image, loss of a loved one, loss of a sense of well-being, and loss of a job.
- Loss, especially loss of a loved one or a valued body part, can be viewed as either a situational or a developmental loss and either an actual or a perceived loss (both of which can be anticipatory).
- Grieving is a normal, subjective emotional response to loss; it is essential for mental and physical health. Grieving allows the bereaved person to cope with loss gradually and to accept it as part of reality.
- Knowledge of different stages or phases of grieving and factors that influence the loss reaction can help the nurse understand the responses and needs of clients.
- How an individual deals with loss is closely related to the individual's stage of development, personal resources, and social support system.
- Caring for the dying and the bereaved is one of the nurse's most complex and challenging responsibilities.
- Nurses' attitudes about death and dying directly affect their ability to provide care.
- Nurses must consider the entire family as requiring care in situations involving loss, especially death.
- Nurses must be knowledgeable about their responsibilities in regard to legal issues surrounding death: advance directives, euthanasia, and do-not-resuscitate orders.
- Dying clients require open communication, physical help, and emotional and spiritual support to ensure a peaceful and dignified death. They need to maintain a sense of control in managing the events preceding death.

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Suggested Readings

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Canadian Nurses Association. (1998b). *Advance directives: The nurse's role*. Ottawa: CNA.

The Canadian Nurses Association (CNA), as part of its mandate to address ethical issues affecting the practice of registered nurses, has prepared this joint statement in collaboration with other national health-related organizations. In considering the range of issues related to end-of-life treatment, the CNA recommends that policy development be guided by this Joint Statement on Resuscitative Interventions and by the Joint Statement on Advance Directives (1994). Technological advance has raised a number of troubling ethical dilemmas. The principles identified in these documents form the basis of decision making about bioethical issues and will be helpful as facilities review their cardiopulmonary resuscitation policies.

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WEBLINKS

Caregiver Network Inc.
http://www.caregiver.on.ca:80/index
Caregiver Network Inc. (CNI), the first of its kind in Canada, is a resource centre created to help caregivers of the elderly and ill. The goal of the network is to make caregivers' lives easier by providing information on the Internet and in a newsletter (see CNI Services); education through the 13-part TV/video series "Caregiving with June Callwood"; the Canadian Aging and Caregiving Resource Guide; and personal assistance and support through seminar series, Care Management Consulting Service, the Caregiver Club, and Care Across the Border.

The Canadian Hospice Palliative Care Association
http://www.cpca.net/about_us/mission_statement.htm
The Canadian Hospice Palliative Care Association (CHPCA) is the national association providing leadership in hospice/palliative care in Canada. CHPCA will strive to achieve its mission through collaboration and representation, increased awareness, knowledge and skills related to hospice palliative care of the public, health-care providers and volunteers; development of national standards of practice for hospice palliative care in Canada; support of research on hospice palliative care; advocacy for improved hospice palliative care policy, resource allocation, and supports for caregivers towards the pursuit of excellence in care for persons approaching death so that the burdens of suffering, loneliness, and grief are lessened.

The University of Ottawa Institute of Palliative Care
http://www.pallcare.org/english.htm
The University of Ottawa Institute of Palliative Care opened in 1993. The pioneers of palliative care development in Ottawa anticipated a growing burden of suffering caused by such diseases as cancer and AIDS in the National Capital Region, and they had the foresight to call for the creation of Canada's first university institute for research and education in palliative care. Since its opening, the institute has offered increased access to information and services in palliative care to patients/clients and health-care professionals.

The Hospice Association of Ontario Life-Line
http://www.hospicelifeline.com
The Hospice Association of Ontario Life-Line provides information about a wide range of hospice/palliative care services and such resources as hospice/palliative care programs, hospice/palliative care units, community-based services, pain and symptom management, bereavement support services, and palliative care education.

CBC

Canadian Case Study — How Does Jackie View Her Role as a Registered Nurse?

Recently, while working on a busy surgical floor during the 3:15 pm to 11:15 pm shift, Jackie, an RN, expressed the view that the ratio of registered nurses to patients was inadequate. On Jackie's unit there were 48 beds divided into three sections, with 16 patients per each. Four registered nurses and three licensed practical nurses were working that evening. Within the first three hours of the shift, two new admissions arrived on the floor as well as three patients who returned from the recovery room. Jackie felt that nursing care was compromised. She felt that the presence of more complex and acutely ill patients in a hospital setting requires more staff. Laschinger and Sabiston (2000) have suggested that massive downsizing in the Canadian health-care system has created a sense of disempowerment and stress among nurses.

Mr. R. was one of Jackie's patients. She had first cared for Mr. R. when he was admitted directly post surgery to the unit two days earlier. He had exploratory surgery to remove a large abdominal mass. The surgery had proven to be of no benefit because of the location of the mass and its interrelationship with several of the abdominal organs. His prognosis was poor. He was extremely uncomfortable despite being medicated. To complicate his recovery, it was felt that he had experienced a small heart attack on the operating room table. He was continually attempting to disconnect himself from his intravenous line and oxygen.

On the day shift, staff had restrained Mr. R's hands. Jackie felt that he was probably feeling helpless and frightened. He kept begging to be put out of his misery, but morally the staff could do nothing. He said to Jackie, "Just let me go, it is my time." The resident had spoken to the family and had written the order "Do not resuscitate" on the chart. Jackie would have liked to spend more time with him so that she could untie his hands but she was too busy. His wife expressed concern that maybe surgery had not been the right decision for her husband and wondered if it was worth the effort. She said to Jackie, "Perhaps he would have lived longer if he did not have the surgery. He certainly would not be in the misery that he is now." Jackie felt frustrated and had wondered the same thing and was not sure what to say to Mr. R's wife.

Jackie felt that some of the staff believed that the morale on the unit was low, and what they felt was systemic and reflective of health care downsizing across the country. Some staff even talked of strike action. Their hesitancy in acting rested, in part, upon their belief that their actions may place patients at risk because resources would be scarce (Forchuk, Fibson, & Best, 1999). They did realize that the administration might well have a srike contingency plan in place.

Jackie recognized that administration was making efforts to empower the nurses on the unit. Possible empowering activities included participating in organizational committees, agency task forces, and development programs; and fostering relationships outside one's immediate work area (Laschinger & Sabiston, 2000).

QUESTIONS

1. Are there any care situations where it may be appropriate to withhold some information from the client? Relate this discussion to Mr. R. and his wife.
2. Relate concepts of professional nursing practice to the care of Mr. R.
3. What elements of nursing practice energize you?
4. What elements of nursing practice de-energize you?
5. What consideration goes into the decision to call a nurses' strike?

VIDEO RESOURCES:

Series Title:	The National
Segment Title:	Patient No More
Telecast Date:	May 3, 1999
Running Time:	11:53
Series Title:	The Health Show
Segment Title:	Informed Consent
Show Number:	85
Telecast Date:	February 15, 1996
Running Time:	7:41
Series Title:	The Health Show
Segment Title:	Palliative Care (Dying at Home)
Show Number:	130
Telecast Date:	March 19, 1997
Running Time:	8:49

Sources: Forchuk, C., Gibson, D., & Best, H. (1999). Strike contingency planning. *The Canadian Nurse, 95*(1), 33–37; Hardingham L. (2001). Ethics in the workplace. Nurses and informed consent: Lessons from the Winnipeg inquest. *Alberta RN, 57*(2), 22–23, 26; Laschinger, H. K. S., & Sabiston, J. A. (2000). Staff nurse empowerment and workplace behaviours. *The Canadian Nurse, 96*(2), 18–22.