**[](http://angel.southseattle.edu/AngelUploads/Files/9cc63e02-ff82-4004-a25e-7d194b7ce500/RobertPaulYounggravestone.jpg)**

Photo Courtesy Robert Paul Young

**Lesson 11: Death and Dying**

**Objectives: At the end of this lesson, you will be able to**

1. **Compare the leading causes of death in the United States with those of developing countries.**
2. **Compare physiological, social, and psychic death.**
3. **List and describe the stages of loss based on various models including that of Kubler-Ross.**
4. **Explain the philosophy and practice of palliative care.**
5. **Describe hospice care.**
6. **Differentiate attitudes toward hospice care based on race and ethnicity.**
7. **Summarize Dame Cicely Saunders' writings about total pain of the dying.**
8. **Compare euthanasia, passive-euthanasia, and physician-assisted suicide.**
9. **Characterize bereavement and grief.**
10. **Express your own ideas about death and dying.**

**"Everything has to die," he told her during a telephone conversation. "I want you to know how much I have enjoyed being with you, having you as my friend, and confidant and what a good father you have been to me. Thank you so much." she told him. "You are entirely welcome." he replied. He had known for years that smoking will eventually kill him. But he never expected that lung cancer would take his life so quickly or be so painful. A diagnosis in late summer was followed with radiation and chemotherapy during which time there were moments of hope interspersed with discussions about where his wife might want to live after his death and whether or not he would have a blood count adequate to let him precede with his next treatment. Hope and despair exist side by side. After a few months, depression and quiet sadness preoccupied him although he was always willing to relieve others by reporting that he 'felt a little better' if they asked. He returned home in January after one of his many hospital stays and soon grew worse. Back in the hospital, he was told of possible treatment options to delay his death. He asked his family members what they wanted him to do and then announced that he wanted to go home. He was ready to die. He returned home. Sitting in his favorite chair and being fed his favorite food gave way to lying in the hospital bed in his room and rejecting all food. Eyes closed and no longer talking, he surprised everyone by joining in and singing "Happy birthday" to his wife, son, and daughter-in-law who all had birthdays close together. A pearl necklace he had purchased 2 months earlier in case he died before his wife's birthday was retrieved and she told him how proud she would be as she wore it. He kissed her once and then again as she said goodbye. He died a few days later (Author's notes).**

A dying process that allows an individual to make choices about treatment, to say goodbyes and to take care of final arrangements is what many people hope for. Such a death might be considered a "good death."  But of course, many deaths do not occur in this way. Not all deaths include such a dialogue with family members or being able to die in familiar surroundings. People die suddenly and alone. People leave home and never return. Children precede parents in death; wives precede husbands, and the homeless are bereaved by strangers.

In this lesson, we look at death and dying, grief and bereavement. We explore palliative care and hospice. And we explore funeral rites and the right to die.

**Most Common Causes of Death (Ob1)**

**The United States:** In 1900, the most common causes of death were infectious diseases which brought death quickly. Today, the most common causes of death are chronic diseases in which a slow and steady decline in health ultimately results in death. How might this impact the way we think of death, how we grieve, and the amount of control a person has over his or her own dying process?

The leading causes of death and number of deaths per category in 2004 in the United States are listed below. (National Vital Statistics Reports, Center for Disease Control, 2006).

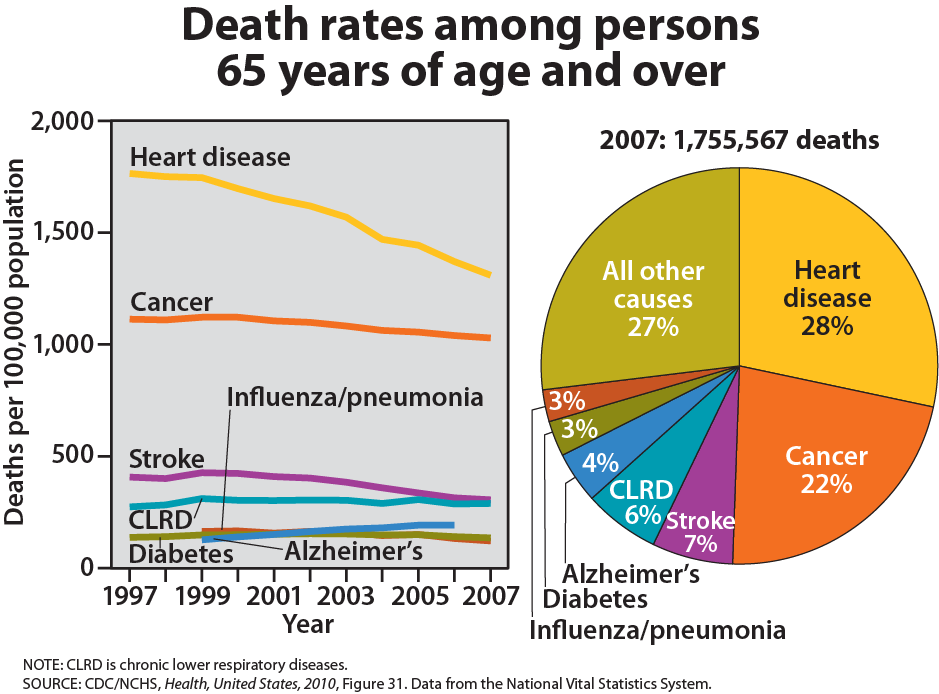
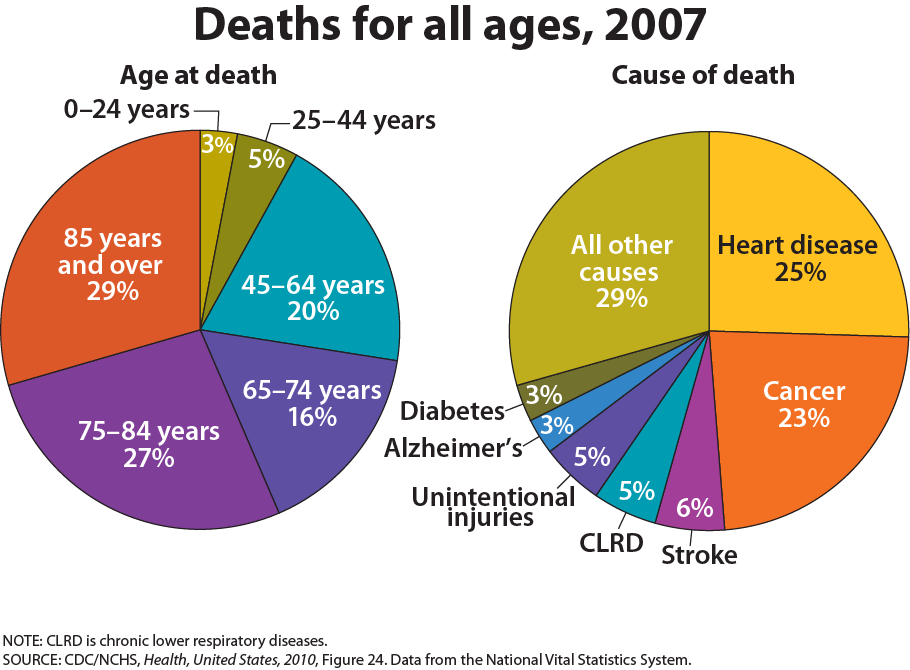
1. Heart Disease (654,092)
2. Malignant neoplasms (cancer) (550,270)
3. Cerebrovascular disease (stroke) (150,147)
4. Chronic lower respiratory disease (123,884)
5. Accidents (123,884)
6. Diabetes Mellitus (106.694)
7. Alzheimer's Disease (72,815)
8. Influenza and Pneumonia (65,829)
9. Nephritis (61,472)
10. Septicemia (42,762)
11. Suicide (33,464)
12. Chronic Liver Disease (31,647)
13. Hypertension and hypertensive renal disease (26,549)
14. Parkinson's disease (22,953)
15. Pneumonitis  (18,018)

These numbers reflect a change in Alzheimer's disease which moved up from the 8th leading cause of death to the 7th and influenza and pneumonia moved down in rank from 7th to 8th.

**Deadliest Diseases Worldwide:**  The top 12 deadliest diseases in the world are listed below along with the estimated number of deaths per cause. These figures are for 2002 and do not reflect deaths due to violence or suicide (World Health Organization, World Health Report, 2004). Notice the higher rates of death due to HIV/AIDS, perinatal conditions and diarrheal conditions than is found in the United States.  Deaths of infants, young children, young mothers, and men and women in adolescence, young adulthood and midlife are more common. Many of these deaths are due to preventable causes. Ideas about the swiftness and unpredictable nature of death are certainly greater when living under such circumstances.

1. Heart disease   (7.2 million)
2. Cerebrovascular disease (5.5 million)
3. Lower respiratory infections (3.9 million)
4. HIV/AIDS (2.8 million)
5. Chronic obstructive pulmonary (2.7 million)
6. Perinatal conditions (2.5 million)
7. Diarrheal diseases (1.8 million)
8. Tuberculosis (1.6 million)
9. Malaria (1.3 million)
10. Trachea, bronchus, lung cancers (1.2 million)
11. Road traffic accidents (1.2 million)
12. Diabetes mellitus (1 million)

**A Comparison of Death by Age in the United States:** A comparison of the causes of death in the United States in the year 2007 for people in late adulthood and among all ages is given below.  Notice that 29 percent of all deaths were of people ages 85 and older and that rates of death due to heart disease had declined since 1997, although heart disease is still the leading cause of death.

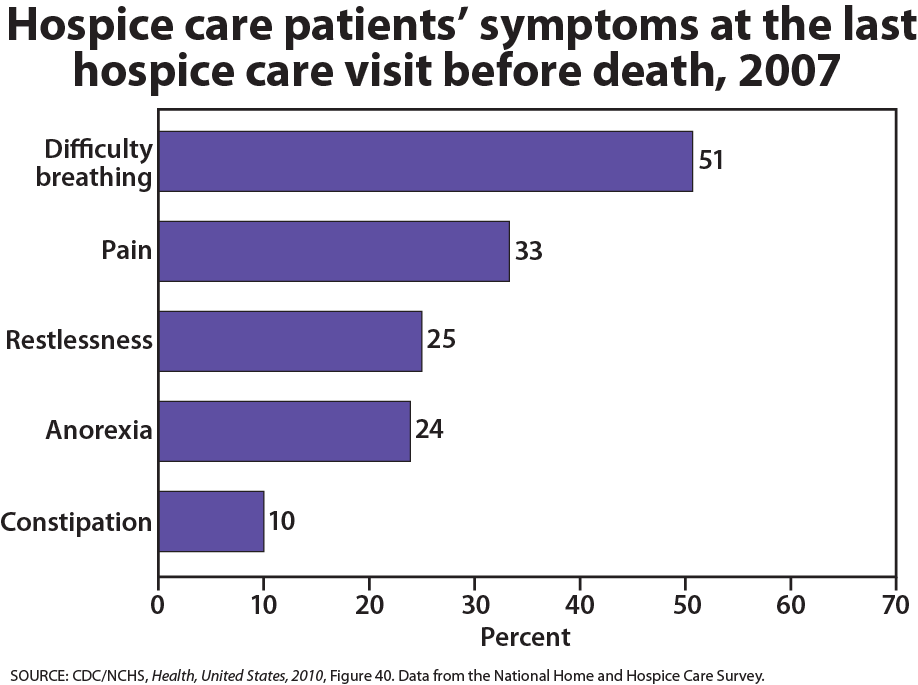
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**The Process of Dying**

**Aspects of Death (Ob2)**

One way to understand death and dying is to look more closely at physical death, psychological death, and social death. These deaths do not occur simultaneously. Rather, a person's physiological, social, and psychic death can occur at different times (Pattison, 1977).

**Physiological death** occurs when the vital organs no longer function. The digestive and respiratory systems begin to shut down during the gradual process of dying. A dying person no longer wants to eat as digestion slows and the digestive track loses moisture and chewing, swallowing, and elimination become painful processes. Circulation slows and mottling or the pooling of blood may be noticeable on the underside of the body appearing much like bruising. Breathing becomes more sporadic and shallow and may make a rattling sound as air travels through mucus filled passageways. The person often sleeps more and more and may talk less although continues to hear.  The kinds of symptoms noted prior to death in patients under hospice care (care focused on helping patients die as comfortably as possible) is noted below.

[](http://angel.southseattle.edu/AngelUploads/Files/9cc63e02-ff82-4004-a25e-7d194b7ce500/hospicesymptomsatdeath.png)

When a person no longer has brain activity, they are **clinically** dead. Physiological death may take 72 or fewer hours.

**Social death** begins much earlier than physiological death. Social death occurs when others begin to withdraw from someone who is terminally ill or has been diagnosed with a terminal illness. Those diagnosed with conditions such as AIDS or cancer may find that friends, family members, and even health care professionals begin to say less and visit less frequently. Meaningful discussions may be replaced with comments about the weather or other topics of light conversation. Doctors may spend less time with patients after their prognosis becomes poor. Why do others begin to withdraw? Friends and family members may feel that they do not know what to say or that they can offer no solutions to relieve suffering. They withdraw to protect themselves against feeling inadequate or from having to face the reality of death. Health professionals, trained to heal, may also feel inadequate and uncomfortable facing decline and death. A patient who is dying may be referred to as "circling the drain" meaning that they are approaching death. People in nursing homes may live as socially dead for years with no one visiting or calling. Social support is important for quality of life and those who experience social death are deprived from the benefits that come from loving interaction with others.

**Psychic death** occurs when the dying person begins to accept death and to withdraw from others and regress into the self. This can take place long before physiological death (or even social death if others are still supporting and visiting the dying person) and can even bring physiological death closer. People have some control over the timing of their death and can hold on until after important occasions or die quickly after having lost someone important to them. They can give up their will to live.

**Five Stages of Loss (Ob3)**

**Kubler-Ross** (1969, 1975) describes five stages of loss experienced by someone who faces the news of their impending death. These "stages" are not really stages that a person goes through in order or only once; nor are they stages that occur with the same intensity. Indeed, the process of death is influenced by a person's life experiences, the timing of their death in relation to life events, the predictability of their death based on health or illness, their belief system, and their assessment of the quality of their own life. Nevertheless, these stages help us to understand and recognize some of what a dying person experiences psychologically. And by understanding, we are more equipped to support that person as they die.

**Denial** is often the first reaction to overwhelming, unimaginable news. Denial, or disbelief or shock, protects us by allowing such news to enter slowly and to give us time to come to grips with what is taking place. The person who receives positive test results for life-threatening conditions may question the results, seek second opinions, or may simply feel a sense of disbelief psychologically even though they know that the results are true.

**Anger** also provides us with protection in that being angry energizes us to fight against something and gives structure to a situation that may be thrusting us into the unknown. It is much easier to be angry than to be sad or in pain or depressed. It helps us to temporarily believe that we have a sense of control over our future and to feel that we have at least expressed our rage about how unfair life can be. Anger can be focused on a person, a health care provider, at God, or at the world in general. And it can be expressed over issues that have nothing to do with our death; consequently, being in this stage of loss is not always obvious.

**Bargaining** involves trying to think of what could be done to turn the situation around. Living better, devoting self to a cause, being a better friend, parent, or spouse, are all agreements one might willingly commit to if doing so would lengthen life. Asking to just live long enough to witness a family event or finish a task are examples of bargaining.

**Depression** is sadness and sadness is appropriate for such an event. Feeling the full weight of loss, crying, and losing interest in the outside world is an important part of the process of dying. This depression makes others feel very uncomfortable and family members may try to console their loved one.  Sometimes hospice care may include the use of antidepressants to reduce depression during this stage.

**Acceptance** involves learning how to carry on and to incorporate this aspect of the life span into daily existence. Reaching acceptance does not in any way imply that people who are dying are happy about it or content with it. It means that they are facing it and continuing to make arrangements and to say what they wish to say to others. Some terminally ill people find that they live life more fully than ever before after they come to this stage.

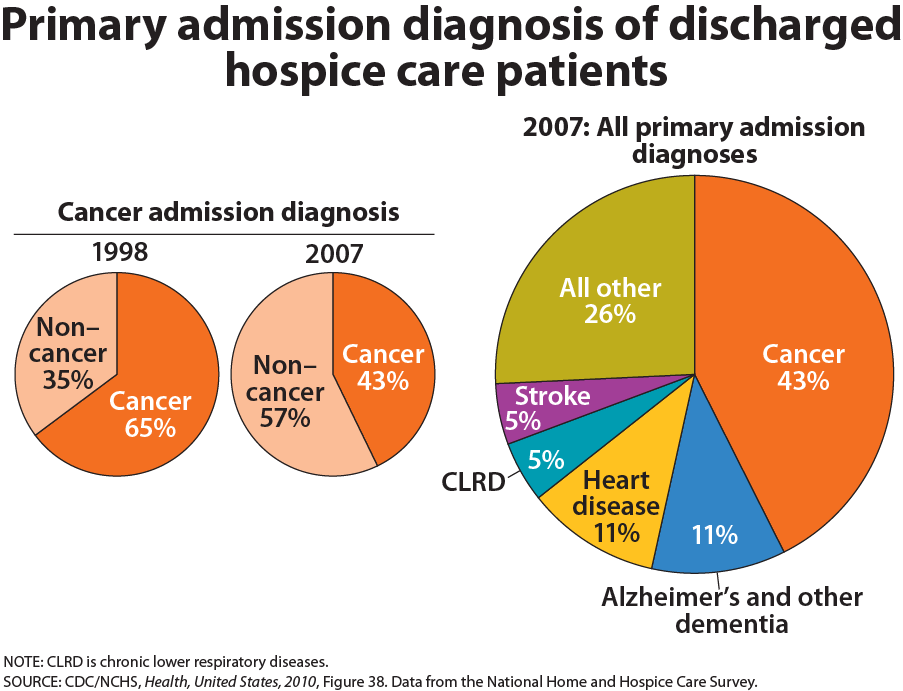
We no longer think that there is a "right way" to experience the loss.  People move through a variety of stages with different frequency and in various ways.

**Palliative Care and Hospice (Ob4, Ob6, Ob7)**

Kubler-Ross's work was introduced at a period in which the hospice movement began in the United States. This movement focused attention on caring for the dying. **Palliative care** focuses on providing comfort and relief from physical and emotional pain to patients throughout their illness even while being treated (NIH, 2007). Palliative care is part of hospice programs. **Hospice** involves caring for dying patients by helping them be as free from pain as possible, providing them with assistance to complete wills and other arrangements for their survivors, giving them social support through the psychological stages of loss, and helping family members cope with the dying process, grief, and bereavement. In order to enter hospice, a patient must be diagnosed as terminally ill with an anticipated death within 6 months. Most hospice care does not include medical treatment of disease or resuscitation although some programs administer curative care as well. The patient is allowed to go through the dying process without invasive treatments. Family members, who have agreed to put their loved one on hospice, may become anxious when the patient begins to experience the death. They may believe that feeding or breathing tubes will sustain life and want to change their decision. Hospice workers try to inform the family of what to expect and reassure them that much of what they see is a normal part of the dying process.

The early hospices established were independently operated and dedicated to giving patients as much control over their own death process as possible. Today, there are more than 4,000 hospice programs and over 1,000 of them are offered through hospitals. Hospice care was given to over 1 million patients in 2004 (NIH, 2007; Senior Journal, 2007). Although hospice care has become more widespread, these new programs are subjected to more rigorous insurance guidelines that dictate the types and amounts of medications used, length of stay, and types of patients who are eligible to receive hospice care (Weitz, 2007). Thus, more patients are being served, but providers have less control over the services they provide, and lengths of stay are more limited. Patients receive palliative care in hospitals and in their homes.

The majority of patients on hospice are cancer patients and typically do not enter hospice until the last few weeks prior to death. The average length of stay is less than 30 days and many patients are on hospice for less than a week (National Center for Health Statistics, 2003). Medications are rubbed into the skin or given in drop form under the tongue to relieve the discomfort of swallowing pills or receiving injections. A hospice care team includes a chaplain as well as nurses and grief counselors to assist spiritual needs in addition to physical ones. When hospice is administered at home, family members may also be part, and sometimes the biggest part, of the care team. Certainly, being in familiar surroundings is preferable to dying in an unfamiliar place. But about 60 to 70 percent of people die in hospitals and another 16 percent die in institutions such as nursing homes (APA Online, 2001). Most hospice programs serve people over 65; few programs are available for terminally ill children (Wolfe et al., in Berger, 2005).



**Dame Cicely Saunders** founded the hospice movement in Great Britain and described the kinds of pain experienced by those who are dying and their families. These 7 Pains include emotional include physical pain, spiritual pain, intellectual pain, emotional pain, interpersonal pain, financial pain and bureaucratic pain. Hospice care focuses on alleviating physical pain and providing spiritual guidance. Those suffering from Alzheimer’s also experience intellectual pain and frustration as they lose their ability to remember and recognize others. Depression, anger, and frustration are elements of emotional pain. And family members can have tensions that a social worker or clergy member may be able to help resolve. Many patients are concerned with the financial burden their care will create for family members. And bureaucratic pain is suffered while trying to submit bills and get information about health care benefits or to complete requirements for other legal matters. All of these concerns can be addressed by hospice care teams.  Learn more about Saunders in the link provided at the end of this lesson.

The Hospice Foundation of America notes that not all racial and ethnic groups feel the same way about hospice care.  African-American families may believe that medical treatment should be pursued on behalf of an ill relative as long as possible and that only God can decide when a person dies.  Chinese-American families may feel very uncomfortable discussing issues of death or being near the deceased family member's body.  The view that hospice care should always be used is not held by everyone and health care providers need to be sensitive to the wishes and beliefs of those they serve (Hospital Foundation of America, 2009).

**Euthanasia (Ob8)**

Euthanasia, or helping a person fulfill their wish to die, can happen in two ways:   **voluntary euthanasia** and **physician-assisted suicide.**Voluntary euthanasia refers to helping someone fulfill their wish to die by acting in such a way to help that person's life end. This can be **passive euthanasia** such as no longer feeding someone or giving them food. Or it can be **active euthanasia** such as administering a lethal dose of medication to someone who wishes to die. 

**Physician-Assisted Suicide**: Physician-assisted suicide occurs when a physician prescribes the means by which a person can end his or her own life. Physician-assisted suicide is legal in Oregon, the Netherlands, Switzerland, and Belgium. The Oregon Death with Dignity Act of 1997 grants physicians this right. Physician-assisted suicides, however, are rare.

A growing number of the population support physician-assisted suicide. In 2000, a ruling of the U. S. Supreme Court upheld the right of states to determine their laws on physician-assisted suicide despite efforts to limit physicians' ability to prescribe barbiturates and opiates for their patients requesting the means to end their lives. The position of the Supreme Court is that the debate concerning the morals and ethics surrounding the right to die is one that should be continued (Stein, 2000). As an increasing number of the population enters late adulthood, the emphasis on giving patients an active voice in determining certain aspects of their own death is likely.

**Bereavement and Grief (Ob9)**

**Bereavement** refers to outward expressions of grief. Mourning and funeral rites are expressions of loss that reflect personal and cultural beliefs about the meaning of death and the afterlife. When asked what type of funeral they would like to have, students responded in a variety of ways; each expressing both their personal beliefs and values and those of their culture.

*I would like the service to be at a Baptist church, preferably my Uncle Ike's small church. The service should be a celebration of life . . .I would like there to be hymns sung by my family members, including my favorite one, "It is Well With my Soul". . .At the end, I would like the message of salvation to be given to the attendees and an alter call for anyone who would like to give their life to Christ. . .*

*I want a very inexpensive funeral-the bare minimum, only one vase of flowers, no viewing of the remains and no long period of mourning from my remaining family . . . funeral expenses are extremely overpriced and out of hand. . .*

*When I die, I would want my family members, friends, and other relatives to dress my body as it is usually done in my country, Ghana. Lay my dressed body in an open space in my house at the night prior to the funeral ceremony for my loved ones to walk around my body and mourn for me. . .*

*I would like to be buried right away after I die because I don't want my family and friends to see my dead body and to be scared.*

*In my family we have always had the traditional ceremony-coffin, grave, tombstone, etc. But I have considered cremation and still ponder which method is more favorable. Unlike cremation, when you are 'buried' somewhere and family members have to make a special trip to visit, cremation is a little more personal because you can still be in the home with your loved ones . . .*

*I would like to have some of my favorite songs played . . .I will have a list made ahead of time. I want a peaceful and joyful ceremony and I want my family and close friends to gather to support one another. At the end of the celebration, I want everyone to go to the Thirsty Whale for a beer and Spang's for pizza!*

*When I die, I want to be cremated . . . I want it the way we do it in our culture. I want to have a three day funeral and on the 4th day, it would be my burial/cremation day . . .I want everyone to wear white instead of black, which means they already let go of me. I also want to have a mass on my cremation day.*

*When I die, I would like to have a befitting burial ceremony as it is done in my Igbo customs. I chose this kind of funeral ceremony because that is what every average person wishes to have.*

*I want to be cremated . . . I want all attendees wearing their favorite color and I would like the song "Riders on the Storm" to be played . . .I truly hope all the attendees will appreciate the bass. At the end of this simple, short service, attendees will be given multi-colored helium filled balloons . . . released to signify my release from this earth. . .They will be invited back to the house for ice cream cones, cheese popcorn and a wide variety of other treats and much, much, much rock music . . .*

*I want to be cremated when I die. To me, it's not just my culture to do so but it's more peaceful to put my remains or ashes to the world. Let it free and not stuck in a casket.*

Ceremonies provide survivors a sense of closure after a loss. These rites and ceremonies send the message that the death is real and allow friends and loved ones to express their love and duty to those who die. Under circumstances in which a person has been lost and presumed dead or when family members were unable to attend a funeral, there can continue to be a lack of closure that makes it difficult to grieve and to learn to live with loss. And although many people are still in shock when they attend funerals, the ceremony still provides a marker of the beginning of a new period of one's life as a survivor.

**Grief** is the psychological, physical, and emotional experience of loss. The five stages of loss are experienced by those who are in grief (Kubler-Ross & Kessler, 2005). Grief reactions vary depending on whether a loss was anticipated or unexpected, (parents do not expect to lose their children, for example), and whether or not it occurred suddenly or after a long illness, and whether or not the survivor feels responsible for the death.    Struggling with the question of responsibility is particularly felt by those who lose a loved one to suicide. There are numerous survivors for every suicide resulting in 4.5 million survivors of suicide in the United States (American Association of Suicidology, 2007). These survivors may torment themselves with endless "what ifs" in order to make sense of the loss and reduce feelings of guilt. And family members may also hold one another responsible for the loss. The same may be true for any sudden or unexpected death making conflict an added dimension to grief. Much of this laying of responsibility is an effort to think that we have some control over these losses; the assumption being that if we do not repeat the same mistakes, we can control what happens in our life.

**Anticipatory grief** occurs when a death is expected and survivors have time to prepare to some extent before the loss. Anticipatory grief can include the same denial, anger, bargaining, depression, and acceptance experienced in loss. This can make adjustment after a loss somewhat easier, although the stages of loss will be experienced again after the death (Kubler-Ross & Kessler, 2005). A death after a long-term, painful illness may bring family members a sense of relief that the suffering is over. The exhausting process of caring for someone who is ill is over.  **Disenfranchised grief** may be experienced by those who have to hide the circumstances of their loss or whose grief goes unrecognized by others.  Loss of an ex-spouse, lover, or pet may be examples of disenfranchised grief.

Yet grief continues as long as there is a loss. It has been said that intense grief lasts about two years or less, but grief is felt throughout life. One loss triggers the feelings that surround another. People grieve with varied intensity throughout the remainder of their lives. It does not end. But it eventually becomes something that a person has learned to live with. As long as we experience loss, we experience grief (Kubler-Ross & Kessler, 2005).

There are layers of grief. Initial denial, marked by shock and disbelief in the weeks following a loss may become an expectation that the loved one will walk in the door. And anger directed toward those who could not save our loved one's life, may become anger that life did not turn out as we expected.  There is no right way to grieve.  A bereavement counselor expressed it well by saying that grief touches us on the shoulder from time to time throughout life.

**Grief and mixed emotions** go hand in hand. A sense of relief is accompanied by regrets and periods of reminiscing about our loved ones are interspersed with feeling haunted by them in death. Our outward expressions of loss are also sometimes contradictory. We want to move on but at the same time are saddened by going through a loved one's possessions and giving them away. We may no longer feel sexual arousal or we may want sex to feel connected and alive. We need others to befriend us but may get angry at their attempts to console us. These contradictions are normal and we need to allow ourselves and others to grieve in their own time and in their own ways.

**The "death-denying, grief-dismissing world"** is the modern world (Kubler-Ross & Kessler, 2005, p. 205). We are asked to grieve privately, quickly, and to medicate our suffering. Employers grant us 3 to 5 days for bereavement, if our loss is that of an immediate family member. And such leaves are sometimes limited to no more than one per year. Yet grief takes much longer and the bereaved are seldom ready to perform well on the job. Obviously life does have to continue. But Kubler-Ross and Kessler suggest that contemporary American society would do well to acknowledge and make more caring accommodations to those who are in grief. Listen to this story about Kubler-Ross and her life and work in the link below.

**Conclusion**

Death and grief are topics that are being given greater consideration. This trend should continue as the population "grays" and our awareness of natural disaster and war, both in the United States and throughout the world grows. Viewing death as an integral part of the lifespan will benefit those who are ill, those who are bereaved, and all of us as friends, caregivers, partners, family members and humans in a global society.

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