CHAPTER 2

CONCEPTS OF DEATH, DYING AND GRIEF

The community needs the dying
to make it think of eternal issues.
We are indebted to those who can make us learn such things
as to be gentle and approach others with true affection and respect.

—Dame Cicely Saunders, M.D.
Founder of the modern hospice movement

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Grief can awaken us to new values and new and deeper appreciations. Grief can cause us to reprioritize things in our lives, to recognize what's really important and put it first. Grief can heighten our gratitude as we cease taking the gifts life bestows on us for granted. Grief can give us the wisdom of being with death. Grief can make death the companion on our left who guides us and gives us advice.

None of this growth makes the loss good and worthwhile, but it is the good that comes out of the bad.

— Roger Bertschausen

I. PERSONAL AWARENESS OF DEATH

In working with hospice and with the issues of death and dying, we will face a number of challenges that may influence our capacity to be *present.* One of the principle reasons we are challenged is due to our current cultural trend to keep a "hands-off" policy in dealing with the terminally ill and the bereaved. This societal attitude is referred to as the *denial of death.*

This section addresses some of the cultural messages that we receive about loss and death, and how these might influence our reactions. Each of us needs to evaluate and define our *own* perspective and attitudes about death. Self-awareness will allow you to more clearly identify situations where you can be available to others, as well as situations where your "blind spots" may interfere with your effectiveness.

Many factors influence our personal awareness of death. Here we address those factors in three parts: socio-cultural influences, the denial of death, and expressing the fear of death.

A. Socio-Cultural Influences

There have been several changes in our society in the last hundred years which have made an impact on our attitude toward death and dying. For example, 100 years ago most people lived in rural areas and frequently witnessed the natural death of animals. During that time, people usually died from an injury or sudden illness, with farm work, factory work, even childbirth, being risky. In 1900, our life expectancy was about 47 years. Today, our life expectancy in the United States is much greater, with men averaging at 76 years and women at 81 years (CDC, 2010). With medical and technological advances, people live longer and can expect to survive several years with an illness that may eventually kill them. These factors create a drastic psychological difference: We just don't expect to die until we are "old."

Geographic dispersion refers to our increased capacity to move quickly from one city to another by plane, train, or automobile. This movement has allowed us to keep a level of physical distance from our family of origin. It is not uncommon now for family members to be spread all over the map. As a result, notification of death is delivered in a much more

impersonal manner, often shared over the phone, for example. The modern urban family experiences death in a much less immediate and impersonal way.

The manner in which death occurs also affects our sense of responsibility. In the 1900s, death was often the result of epidemics, bacterial infections and other diseases over which we had little control. Today, the most common causes of death are cancer and heart disease. Many of us feel we have more control over these ailments and believe we can protect ourselves against them.

In the 1900s, deaths commonly occurred in the home and medical technology was limited. Today, 80% of deaths occur in institutions. Those in medical professions are taught to try and preserve life, almost at any cost. Our technological advances have prompted many lawsuits about issues of death and dying. Therefore, malpractice litigation plays a role in the medical profession's approach to do everything they can to preserve life.

This attitude to "beat the disease" extends beyond the medical profession. It is part of our American value system to be "winners" at any cost. While our educational system constantly teaches us how to acquire things and accomplish goals, we are given very little information about how to cope with loss. Author R. A. Kalish writes in the book *Death, Grief, and Caring Relationships*, "In our society we are uncomfortable in the face of certain kinds of failure, certain kinds of intimacy, certain kinds of loss, and we are led to believe that others are similarly uncomfortable" (p. 87).

Our self-esteem is often wrapped up in our identity, and for many modern Americans, identity includes job, appearance, money, and material possessions. When a person is seriously ill, they often lose part of their identity. As Stephen Levine discusses in his book *Who Dies? An Investigation of Conscious Living and Conscious Dying*:

> We have become so identified with our doing, with our model of who we are, that we become incredibly insecure at the time of death. We no longer know who we are, because we have always traded off our true being for some stance in the world, for some position of authority. We have traded grace for the mask of someone doing something in a world of arbitrary values (pp. 55-56).

Society presents us with a rather strident irony. On one hand, we receive a barrage of images of violence and death on both TV and in the movies, creating a visual *blitzkrieg*, watching murder after murder, and desensitizing the death experience. (A basic tenet of behavioral psychology is that the more one experiences a stimulus, like death on TV, the less one will react to it.) On the other hand, when we personally experience the loss or death of someone close to us, we are encouraged not to acknowledge it.

B. Denial of Death

Denial refers to our unconscious attempt to insulate ourselves from some knowledge. Dr. Ira Byock, a palliative care physician and a past president of the American Academy of Hospice and Palliative Medicine, remarks that, "Usually, when family members aren't talking about dying one of two things is happening: Either a) there is unwillingness on the part of the person or a family member to acknowledge that the illness is progressing, or b) dying is on

everyone's mind, but there is a conspiracy of silence in a misplaced attempt to protect one another from discussing painful feelings and deepest fears."

There are concrete reasons for the development of this denial, such as early socialization, natural separation anxiety, and fear of the unknown. As mentioned previously, we are generally disconnected or insulated from death experiences. For example, when a small child's pet dies, the family often deals with the loss by acquiring a "replacement" pet. In that case, the child receives the message that it is not okay to talk about death.

Secondly, the fear of separation, or losing someone close, is also a psychological threat to us. This is not only because others in our lives provide us with a sense of security, but often because of the underlying childhood fear that we will be abandoned and unable to take care of ourselves. What will life be like without that person?

The fear of the unknown can create psychological unrest. Although some people have a belief in an "afterlife," many are left wondering. Thinking about death is often uncomfortable and, therefore, commonly repressed or denied.

C. Expressing the Fear of Death

Society helps deny that death exists by limiting its acknowledgment of it. As psychologist Richard Kalish (1985) writes:

> Society provides many specific safeguards to permit us to avoid contact with death and dying. It provides institutions for the dying, encourages the use of euphemisms in discussing death, makes certain that the death-related aspects of funeral homes are not conspicuously displayed either in advertising or on buildings. . . (p. 98)

The psychological need to express our fear of death is not overlooked, particularly by the "existential" psychologists. Irvin Yalom (1985) writes:

> Certainly, the knowledge of our isolation, our destiny and our ultimate death deeply influences our conduct and our inner experience. Though we generally keep them out of awareness, the terrifying contingencies of our existence play upon us without end. We strive to dismiss them by enveloping ourselves in life's many diversions, or we attempt to vanquish death. . .(p. 182)

If we were completely conscious of death all the time, it could become a fearful obsession. Yet, on the other end of the spectrum, continued avoidance adds to the burden of not knowing what to do, how to act, or how to be when death or loss unexpectedly comes.

By participating in this hospice training experience, you will have the opportunity to confront any resistance you may have to the topic of death. In fact, because you have signed up for the training, in all likelihood you have already begun to acknowledge death and loss as a part of life. Through your growth, you may be able to talk honestly and openly about death with your loved ones and clients. One way to begin is to be unembarrassed about the fact that, eventually, everyone dies.

II. CLIENT AND FAMILY AWARENESS OF DEATH

When you visit a home as a Hospice SLO volunteer, you will be arriving with the knowledge that individuals and families are all different, and that all families will be dealing with terminal illness in unique ways. Some might arm themselves with humor, others with intellect (the need to "understand" the illness), or some with straight denial ("She'll get better, just watch"). Whatever the individual's or family's coping style, it is very important to remember that it is not our job to try and change them. However, being able to appreciate the defense mechanisms and coping strategies that families use will be helpful in understanding them.

A. Client and Family Needs During Crises

Research suggests that family crises arise from a "stressor event." The stressor event interacts with both the family's current crisis-meeting resources and the family's definition or perception of the stressor. The family's ability to cope is affected by other stressors happening at the same time. Each family's resources and their perception of the events will influence how they cope.

Concurrent Stressors

The family may already be dealing with other stressful situations prior to the onset of a terminal illness. Stressors related to the illness may include caregiving and the anticipation of the loss of family life as it was before, or the loss of the roles the person played in the family. It is also possible that careers will be interrupted and that the family will experience financial strain.

Concurrent stressors not related to the illness may be the recent death of another relative, moving, or occupational change.

Family Resources

When we talk about family resources, we are referring to both the support inside the family as well as that outside the family. The resources inside the family refer to how well the members interact, and their ability to integrate and adapt to the changing situation.

Even with the most well-adjusted and communicative of families, however, it is important that they have some external resources. Researchers have found that in order to cope well, families *must* also develop or strengthen these outside resources. It has been observed that families who had a high level of functioning sought both practical help and emotional support from persons both inside and outside the family.

Family's Perception of the Event

It is often not the event, but the significance we attach to it that makes it pleasant or unpleasant for us. Similarly, a family's perception of an impending death will greatly influence their ability to cope with it. Factors such as religious beliefs or psychological understanding may play major roles in a family's reaction. When there is "unfinished business" regarding personal relationships, family members' stress levels may increase.

It is not your responsibility as a volunteer to aid in changing the family's perception, but rather to provide support to whatever system works for the family.

III. LOSS AND GRIEF: CRISES FROM CHANGE AND FROM ANTICIPATED DEATH

Often, as an In-Home volunteer, you will feel you are part of the family until your hospice client dies. Therefore, it is important to be aware of a few things about a family's reaction to the death.

As loved ones deal with the patient's declining health, they may experience what is known as *anticipatory grief*. According to Dr. William Worden, there is no substantial evidence that those who are forewarned of an imminent death will have any better post-death resolution of their grief.

No matter how long the person has been ill, or terminal, the actual death usually produces a feeling of shock in the survivors. Along with this feeling comes several other emotions — guilt, resentment, depression — all of which produce a new crisis state for the caretaker and family. In Chapter 7 of this manual, we will discuss family systems in detail and provide some helpful tools for understanding how you can support family members.

A. Spiritual Dimensions of Dying

Over time, Western medicine has separated physical care from a person's spiritual needs. Increasingly, however, there is recognition of the importance of spirituality in the care of dying people. Numerous studies have been done that support the important role spirituality plays in patient care. When medicine confronts life-limiting illness, in particular, and when a cure becomes less likely, it is of paramount importance to help patients cope with their suffering and eventual death.

Often, a person's sense of spirituality becomes magnified as death approaches. For example, a person's strong belief in an afterlife may impart more hope and meaning to the dying process. As people near death they often wrestle with questions such as "Why me?" or "What will happen to me?" or "What has my life meant?" These are inherently issues of the spirit, not only of biology or chemistry. Physicians and other health care providers increasingly recognize that good care of dying people is as much or more about these questions as it is about the relief of pain and other symptoms. Spirituality is an expression of how people relate to a larger whole—something greater than themselves—and how they find meaning in the midst of their suffering. A person's purpose and meaning in life can be expressed in different religious traditions, a deep regard for nature, connections to family, art and music, or in some other way that is uniquely personal.

One discernible way to assess someone's spiritual beliefs is by their expressed religious convictions. Religion can be defined in terms of denominational affiliation, church attendance, or the performance of prayers and other rituals. It can be understood as adherence to a set of beliefs or having had feelings or experiences that people will agree are "religious."

1. Special Communication of the Dying

Before presenting an overview of some of the specifics of different religions with their rituals and philosophies of death and dying, it is important that we include a short segment on some common occurrences which have been noted to occur prior to death. These experiences, called "Nearing Death Awareness," do not occur in all dying people, but have happened enough that it is important that you, as a volunteer, are aware of the characteristics. These behaviors have obvious spiritual overtones.

We are including the article, *Is this Confusion, or a Special Communication of the Dying?* by Kelley and Pflaum, which explains "Near Death Awareness."

IS THIS CONFUSION, OR A SPECIAL COMMUNICATION OF THE DYING?

Patients who are dying slowly often develop a Nearing Death Awareness, a special knowledge and sometimes control of the dying process and of what they need in order to die peacefully. Often, the patients attempt to describe what is happening during the process of dying. Unfortunately, a final request may be missed, misunderstood, or ignored because the communication is sometimes obscure and unexpected. The request may be expressed in symbolic talk, the language relating to his or her own lifestyle of experiences. Hospice workers who listen carefully may be able to understand the patient's awareness, control, and requests, and help families understand and participate more fully in this important event.

Many times as a person is dying, in the last hours, days, or weeks of life, he or she may say something which does not immediately seem to make sense. Often the people who are with the dying quickly label this. Family members may say, "her mind is wandering"; staff may say the person is "confused." We notice that family and friends are often much more distressed by the apparent "loss of mind" rather than the patient's physical losses and problems. They may respond with frustration or fear or attempt to humor or re-orient the dying person. Sometimes, sadly, the staff may attempt to alter it by medication. But everyone stops really listening. These responses only distance the patient more from those around him and produce a sense of isolation and bewilderment. However, no matter what, if any physiological changes may be causing the confusion, the "confused" talk of the dying may be significant symbolic communication. By listening carefully we can sometimes begin to understand.

Common Themes and Possible Interpretations:

1. Describing place
2. Talking to or being in the presence of someone who is not alive
3. Knowledge of when death will occur
4. Choosing the time of death
5. Needing reconciliation
6. Preparing for travel or change

The first two themes are very common. Many people speak of "being in another place" and not only when death is imminent. Days or weeks before death a person may say, "I had a dream, but it wasn't really a dream. I was in such a lovely place..."

Also, patients tell us about seeing or talking with someone we cannot see. These are often people the patient loved who are dead already, though "a loving, caring presence" may be used to describe someone they do not know.

Knowledge of when death will occur is also common, but also is often missed. A person may say to us in August, "Christmas can be sad" and die on Christmas day (as she warned us four months before).

These three themes (and others) seem to be a patient's attempt to tell us about what is happening during the dying process. It is important to listen carefully and help the patient explore what is happening, if he or she is able, or wants to.

Families often need us to explain that these are not hallucinations caused by drugs, confusion related to physiological changes, or signs of mental deterioration. They need to know that fairly frequently dying people seem to have glimpses of "another world" and loved ones waiting for them. The patient's increased awareness of what happens during dying and death may also include how long it may take.

The next themes fit into a general category of increased knowledge of what is necessary for the death to be peaceful.

Choosing a time of death, the idea of someone holding on until after a special person has arrived, is familiar to many; but we also see death apparently timed for when an important person is not there. Or there but with others to give support. How many times does a patient die just after the hospice nurse arrives, or in the only 5 minute period in a week that he was alone? If the patient dies alone, the first reaction for the family (and sometimes the staff) is guilt, "I wasn't there." But, maybe the patient chose to die alone, as a gift to spare loved ones.

Needing reconciliation has many variations. Often a dying person's "confused" talk can be interpreted as a request for a meeting, reconciliation, or healing of a relationship. Sometimes what the patient needs is recognition of what is happening to him and permission to die.

The patient's struggle "to stay or to go" is a particularly poignant message of love and concern. Many families are able to resolve this dilemma by telling the patient that they appreciate the patient's "fight," but are ready, although sadly, to let him or her go, with the assurance that the family will be all right. This is often the final "permission" a patient needs to let go and die peacefully.

2. Differing Religious Viewpoints

There are hundreds of organized religions in the world, all of them with their own unique attitudes about death and dying. Therefore, we are initially going to discuss only a few of the more common religions in this geographic area.

All people, even those within the same religion, will deal differently with the death and dying process. In hospice work we respect and appreciate the differences among religions and people, attempting to understand, yet not categorize.

a. *THE PROTESTANT VIEW OF DEATH* by Reverend Barbara J. Haddon, MDiv.

It is difficult to speak for the wide spectrum of Protestant faith in one statement regarding our approach to death and dying, as there is a wide spectrum of theology among those of us who are Christian but not Catholic. However, there are some generalizations which can be made which will probably be found acceptable among those of this faith.

We believe that God desires community and communication between the Holy One and humanity. The stories of both Old and New Testaments in the Bible recount God's repeated attempts to bring humanity into obedience and community with our loving God. Part of that desire is not only to be in touch with us during our earthly life, but also to provide life eternal in fuller community with God following our death. All Protestants believe in life eternal with God following life on earth. We differ in our understanding of what form that life will take. Some believe in a bodily resurrection, while others understand that it is the spiritual nature that continues to reside with God after this life.

What we believe about the form of the earthly body as it enters the hereafter influences our practices regarding the disposition of the earthly body and burial practices. Those who believe that the body will be transformed in the afterlife have no difficulty accepting the practice of cremation, and may either bury or scatter the ashes. They may also choose traditional burial. Those who believe that the earthly body is transformed into perfection but remains basically in the same form choose burial only.

Because we believe that we will be united with God following our death, we teach that death is not to be feared. While we recognize the difficulty of the dying process, and we understand and sympathize with the grieving process undergone by the dying person and their family and friends, we nevertheless teach that we need not fear death. Before death occurs, time is spent with the family and friends sharing not only the psychological pieces which prepare a patient and loved ones for dying, but also sharing passages from Scripture, both Old and New Testaments, which will bring comfort to those in grief. Passages from the Psalms (Old Testament) and from the Gospels and Paul's letters (New Testament) are often helpful.

At the time of death, most Protestant clergy will encourage a memorial service or funeral as a way of providing closure and an expression of grief for the survivors. Again, those who do not place importance on the physical body may choose a memorial service. If the casket is present, however, it will be closed during the service. The emphasis is not on the body, but on the celebration of life completed and the resurrection to eternal life which we understand to be one of the promises of God. The service may include the singing of hymns, especially those that are meaningful to the deceased or the family. The service will always include prayer and Scripture, and may include memories of the deceased or a meditation on the Scriptures. Scriptures commonly used during the service are the 23rd Psalm, Psalm 139, Psalm 121 (Old Testament) and John 14, I Corinthians 15, and Romans 8 from the New Testament. Emphasis is always on claiming the promise of resurrection and the hope of eternal life. The dual focus of such a service is to acknowledge the grief of the survivors while celebrating the life of the deceased, and at the same time to help the congregation look forward with the assurance that "pain has ended and death is past." The hope and expectation is in the resurrection and the life eternal with God. The promise is claimed both as an accomplished fact for the deceased and a real hope for the survivors.

Some Protestants believe that upon death, the soul or the transformed body are united immediately with God; that is, that resurrection is immediate and individual. Others believe that there will be one great "rapture" at the time that the world ends and God in Christ will bring all believers together from all times and places to be united with God, while those who have not believed will be separated from God forever. Some Protestants put greater emphasis on judgment, while others emphasize forgiveness.

It is important that care and attention to the survivors not end with the funeral or memorial service, but that they have an opportunity to continue to process their grief, to discuss faith questions, and to deal with issues of their own mortality which are often raised at the time of death of a loved one. Death needs to be seen as part of life; not an event to be feared, but rather part of the cycle of God's eternal plan for humanity.

b. *THE JEWISH WAY* by Rabbi Earl A. Grollman, D.D.

Jewish Ceremonies of Death

For children as well as adults, the ceremony surrounding death is of enormous significance. The Jewish faith suggests rites that play a vital role in the healing work of grief. The bereaved must realize that a loved one is gone and that the void must be filled gradually in a constructive way. He should not suppress memories or the memories of disturbing, even guilt-producing relationships. Rather, shock and grief are structured by definite and solemn procedures.

The wise parent should discuss the Jewish customs relating to death in a gentle and non-threatening manner. The child should not have to wait until the death of a loved one to be hurriedly and frantically informed by a weeping mother that people are buried in special gardens or that stones or plaques are placed on each grave to indicate who is resting there. It is suggested that one explain the realities of death under more ideal circumstances, rather than with retroactive interpretation in the face of grief.

The Funeral: When death does occur, a child should be encouraged to attend the funeral. To shut a youngster out of this experience might be quite costly and damaging to his future development. He is an integral part of the family unit and should participate with them on this sad but momentous occasion. However, if the child is unwilling, he should not be forced to go or made to feel guilty because "he let the family down." If he does not attend the funeral, it may be wise to provide an opportunity at some later time to visit the cemetery and see the grave.

In Judaism, from the moment that one learns of the passing of a dear one, there are specific religious rituals to be followed which help to order one's life. The Jewish funeral is a rite of separation. The bad dream is real. The presence of the casket actualizes the experience. It transforms the process of denial to the acceptance of reality. The service itself is relatively brief and is devoted to prayers and to a description of the loved one's life and qualities that might be perpetuated by the living.

The funeral might begin at the funeral chapel or synagogue. However, it does not end there, but rather at the cemetery. This is the final resting place.

Mourners: One becomes a mourner (Hebrew, *ovel*) upon the death of one of seven relatives: father, mother, husband, wife, son or daughter, brother or sister, including half-brother or half-sister.

A child less than thirteen years old is not obligated to observe all the rites of mourning.

Mourning Period: The word *shivah* in Hebrew means "seven days of mourning." It begins immediately after the funeral, with the day of burial counted as the first day. One hour of the seventh day is considered a full day. During the week of *shivah*, the mourners remain home, with the exception of the Sabbath and Festivals, when the family attends Temple Worship Service. It is customary to wear dark clothing during this period, preferably black. A memorial light burns in the home during the shivah week. The mourners do not work during this time, except if they are compelled to do so from necessity, and then are allowed to do so only after three days have elapsed. Morning and evening services are frequently held in the home.

The thirty-day period of mourning is known in Hebrew as *sh'loshim*, beginning on the day of the funeral and ending on the 30th day. Mourners do not take part in any festivity or amusement during this period. The graves of the deceased are not visited.

Kaddish: Mourners recite *kaddish* for a period of eleven months from the date of burial. The mourner rises in the Synagogue during the reading of the mourner's kaddish. The mourner especially attends the Sabbath Services for these eleven months. If the mourner is unable to attend, appropriate psalms and meditations can be recited at home.

Yahrzeit: The anniversary of the death of a relative (*yahrzeit*) is observed by attending the Temple Worship and reciting the mourner's kaddish.

Unveiling: The time for the dedication of the memorial plaque or tombstone is toward the end of the first year of interment. Unveiling is, of course, not held on the Sabbath or Festivals.

LAWS FOR GOVERNING GRIEF **by Rabbi Joshua L. Liebman**

Peace of Mind

The first law to be followed in the time of the loss of a loved one is: express as much grief as we actually feel. Do not be afraid of breaking down under the strain of your loss. The pain that we feel now will be the tool and instrument of our later healing.

Secondly, we must learn to extricate ourselves from the bondage of the physical existence and co-existence of the loved ones. The melody that the loved one played upon the piano of our life will never be played quite that way again, but we must not close the keyboard and allow the instrument to gather dust. We must seek out other artists of the spirit, new friends who gradually will help us to find the road to life again, who will walk on that road with us.

We should not resist the sympathy and the stimulation of social interaction. We should learn not to grow impatient with the slow healing process of time. We should discipline ourselves to recognize that there are many steps to be taken along the highway leading from sorrow to renewed security. We should anticipate these stages in our emotional convalescence: unbearable pain, poignant grief, empty days, resistance to consolation, disinterestedness in life, gradually giving way under the healing sunlight of love, friendship, social challenge, to the new weaving of a pattern of action and acceptance of the irresistible challenge of life.

c. ***CATHOLIC RITUALS FOR MOURNERS AND THEIR DEAD*** **by Father N.H. Cassem, S.J., M.D.**

Theological Viewpoint

Rituals of the Catholic Church for the period of death and mourning reflect doctrines surrounding the mysteries of the suffering, death, and resurrection of Christ. By identifying believers as sharers in the saving grace of Christ, the Church also marks them as sharers in the Paschal (Easter Passover) Mystery of Christ — which at root states that he overcame suffering and death (by rising from the dead) by suffering and dying himself. Therefore, all rituals that surround death will reflect and recall these events in the life of Christ. A frequent quotation expressing these beliefs occurs in St. Paul: "If the Spirit of him who raised Jesus from the dead dwells in you, then he who raised Jesus Christ from the dead will also bring to life your mortal bodies because of his Spirit who dwells in you" (Rom. 8:11).

The Three Catholic Rituals

There are basically three rituals of the Catholic Church for the dead: 1) the wake, 2) the funeral and 3) the burial.

1) *The Wake*: The purpose of the Church in holding a vigil or wake for the dead person is to provide an opportunity for the mourners to pray for him. In addition, it is meant to provide a time for reflection on the meaning of life, death, and eternal life (the latter purpose is seldom made explicit). The wake was formerly held in the home. It still could be. This choice is the family's. Customs at wakes vary. No definite rituals are required by the Church. Usually some service occurs during the one or two days of the wake. Casket may be open or closed and the setting formal

or informal. The service varies from nothing to recitation of the rosary to Pentecostal prayer meeting. The Roman Ritual reminds the reader that the chief guide is the needs of the people involved.

2) *The Funeral*: This usually begins with a procession from the funeral home to the church. The funeral mass, now celebrated with white vestments instead of black (because of the emphasis on the resurrection of Christ, a rather recent trend in Christian theology), proceeds. The casket is draped in white, as a symbol of the white robe of baptism. The paschal candle (lit at Easter, then kept through the year) stands by the casket. The change from black to white has also been used to emphasize the belief that the joy of faith overcomes death. (Black was also dropped because it lent itself so much to the penitential motif that had grown to an almost morbid preoccupation with the sins of the deceased.) The readings for the service should be chosen by the family. Traditionally the homily (sermon) delivered was always by the priest and often not a personal eulogy of the dead person. This is also changing; the rites leave this entirely open. Again, arrangements of the music are meant to serve the individual needs of the family.

3) *The Burial*: The Roman Ritual explicitly states the purpose of this final portion of the services: it is "a rite of final commendation and farewell." It is meant as a climax to services, an actual chance for the mourners to say their farewell. Again, no set of rites at the grave are required, but usually the grave is blessed and reading of scriptural passages and prayers occurs. Singing may be included. The family can stay for the lowering of the casket into the ground (this should always be decided beforehand), though most seem not to.

Engagement of the family in the choice of forms for these rituals is considered to lie at the heart of the pastoral obligation to them. It is in this planning that much grief work is done and further successful work ensured. The same engagement of the family in planning by the funeral director also lies at the heart of his compassionate service to their needs.

The Fourth Ritual and Other Customs: Although not a religious ritual, it is usually customary for mourners and friends to return from the grave to the home of the deceased family. As is well known, custom varies widely as to how this is conducted, but its success depends not on ritual but on the love of friends and their skills at knowing how to be sympathetic and be themselves. The Church views this as part of the obligation of the community of believers to one (or several) of their members.

Cremation is allowed for those Catholics who choose it. Rituals could easily include the crematorium as a site. After death, parishes celebrate commemorative masses for the deceased with special masses, monthly if the family wishes them.

d. ***MY FAITH*: What people talk about before they die -Kerry Egan**, Special to CNN January 28, 2012

***Editor's Note**: Kerry Egan is a hospice chaplain in Massachusetts and the author of "Fumbling: A Pilgrimage Tale of Love, Grief, and Spiritual Renewal on the Camino de Santiago."*

As a divinity school student, I had just started working as a student chaplain at a cancer hospital when my professor asked me about my work. I was 26 years old and still learning what a chaplain did.

"I talk to the patients," I told him.

"You talk to patients? And tell me, what do people who are sick and dying talk to the student chaplain about?" he asked.

I had never considered the question before. "Well," I responded slowly, "Mostly we talk about their families."

"Do you talk about God?

"Umm, not usually."

"Or their religion?"

"Not so much."

"The meaning of their lives?"

"Sometimes."

"And prayer? Do you lead them in prayer? Or ritual?"

"Well," I hesitated. "Sometimes. But not usually, not really."

I felt derision creeping into the professor's voice. "So you just visit people and talk about their families?"

"Well, they talk. I mostly listen."

"Huh." He leaned back in his chair.

A week later, in the middle of a lecture in this professor's packed class, he started to tell a story about a student he once met who was a chaplain intern at a hospital.

"And I asked her, 'What exactly do you *do* as a chaplain?' And she replied, 'Well, I talk to people about their families.'" He paused for effect. "And *that* was this student's understanding of faith! *That* was as deep as this person's spiritual life went! Talking about other people's families!"

The students laughed at the shallowness of the silly student. The professor was on a roll.

"And I thought to myself," he continued, "that if I was ever sick in the hospital, if I was ever dying, that the last person I would ever want to see is some Harvard Divinity School student chaplain wanting to talk to me about my family."

My body went numb with shame. At the time I thought that maybe, if I was a better chaplain, I would know how to talk to people about big spiritual questions. Maybe if dying people met with a good, experienced chaplain they would talk about God, I thought.

Today, 13 years later, I am a hospice chaplain. I visit people who are dying – in their homes, in hospitals, in nursing homes. And if you were to ask me the same question - What do people who are sick and dying talk about with the chaplain? – I, without hesitation or uncertainty, would give you the same answer. Mostly, they talk about their families: about their mothers and fathers, their sons and daughters.

They talk about the love they felt, and the love they gave. Often they talk about love they did not receive, or the love they did not know how to offer, the love they withheld, or maybe never felt for the ones they should have loved unconditionally.

They talk about how they learned what love is, and what it is not. And sometimes, when they are actively dying, fluid gurgling in their throats, they reach their hands out to things I cannot see and they call out to their parents: Mama, Daddy, Mother.

What I did not understand when I was a student then, and what I would explain to that professor now, is that people talk to the chaplain about their families because that is *how* we talk about God. That is *how* we talk about the meaning of our lives. That is *how* we talk about the big spiritual questions of human existence.

We don't live our lives in our heads, in theology and theories. We live our lives in our families: the families we are born into, the families we create, the families we make through the people we choose as friends.

This is where we create our lives, this is where we find meaning, this is where our purpose becomes clear.

Family is where we first experience love and where we first give it. It's probably the first place we've been hurt by someone we love, and hopefully the place we learn that love can overcome even the most painful rejection.

This crucible of love is where we start to ask those big spiritual questions, and ultimately where they end.

I have seen such expressions of love: A husband gently washing his wife's face with a cool washcloth, cupping the back of her bald head in his hand to get to the nape of her neck, because she is too weak to lift it from the pillow. A daughter spooning pudding into the mouth of her mother, a woman who has not recognized her for years.

A wife arranging the pillow under the head of her husband's no-longer-breathing body as she helps the undertaker lift him onto the waiting stretcher.

We don't learn the meaning of our lives by discussing it. It's not to be found in books or lecture halls or even churches or synagogues or mosques. It's discovered through these actions of love.

If God is love, and we believe that to be true, then we learn about God when we learn about love. The first, and usually the last, classroom of love is the family.

Sometimes that love is not only imperfect, it seems to be missing entirely. Monstrous things can happen in families. Too often, more often than I want to believe possible, patients tell me what it feels like when the person you love beats you. They tell me what it feels like to know that you are utterly unwanted by your parents. They tell me what it feels like to be the target of someone's rage. They tell me what it feels like to know that you abandoned your children, or that your drinking destroyed your family, or that you failed to care for those who needed you.

Even in these cases, I am amazed at the strength of the human soul. People who did not know love in their families know that they *should* have been loved. They somehow know what was missing, and what they deserved as children and adults.

When the love is imperfect, or a family is destructive, something else can be learned: forgiveness. The spiritual work of being human is learning how to love and how to forgive.

We don't have to use words of theology to talk about God; people who are close to death almost never do. We should learn from those who are dying that the best way to teach our children about God is by loving each other wholly and forgiving each other fully - just as each of us longs to be loved and forgiven by our mothers and fathers, sons and daughters.

The opinions expressed in this commentary are solely those of Kerry Egan.

Cultural Dimensions

All people and families have a right to deal with their crises and grief in their own way. The understanding that different backgrounds will influence behavior differently will help us to be open to whatever experience the family is having. It is important for us to approach each new situation with an attitude of openness and a willingness to learn, avoiding generalizations and remembering that all people should be viewed as individuals first and foremost.

The following may be expressions of cultural difference in the dying process:

- No one in the family will acknowledge or talk about the fact the client is dying.
- Acupuncture, acupressure, herbal teas and vitamins, and special foods are uses as alternatives to Western medicine.
- During the funeral, family and loved ones throw themselves on the body.
- The family will talk to a hospice volunteer or staff member only when the head of household is present.
- The family sees illness as a punishment for misdeeds.
- When the loved one has died the family covers all mirrors in the home.

San Luis Obispo County's population includes people from various cultural and ethnic backgrounds. As a volunteer, when you come across a family's culture that is unfamiliar to you, you are encouraged to learn about their beliefs and traditions through your own research. You may respectfully inquire about the cultural traditions this family holds. This can be a valuable tool while you build a relationship with the client and their family.

IV. SUMMARY

In this section, we touched on a number of areas that are related to the concepts of death, dying, and grief. Some of the material is geared toward an understanding of what the client

and family may be going through as well as their rights and responsibilities. As a volunteer-in-training, your responsibility during this training is to become more aware of your sensitivities toward death and dying. This process can be both difficult and exhilarating as we confront a topic that we have been conditioned to avoid.

As a volunteer for Hospice SLO, you may encounter religious and cultural views that differ from your own. Our work in the community is to support families in their own process in dealing with loss and end of life issues. When we are open-minded and compassionate, we can better support the needs of the bereaved in our community.

As you venture down this path, do not forget to utilize the Hospice SLO staff. Ask questions, use their support, and open yourself to growth.

NAME: _____

CHAPTER 2 REVIEW
CONCEPTS OF DEATH, DYING AND GRIEF

1. Give at least three societal influences that have impacted our view of death since the turn of the century.

2. Provide a personal example of someone you know who, at one time, "*denied death*."

3. What are two patient and/or family needs during a crisis?

4. Write down four possible themes that may be communicated by someone who is dying.

5. Write down one thing you learned about a religious view of death and dying that you didn't know prior to reading this section.