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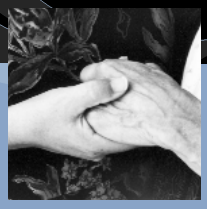
THE COMPLETE LIFE


A Guidebook for Those Who Minister to the Dying & the Bereaved

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PREFACE

"If we wish to die well, we must live well."

– His Holiness The Dalai Lama

Death is perhaps the most mystical and mysterious moment of human existence. Many believe it is a step that bridges two worlds. To be allowed entrance into another's personal and intimate journey of dying is a sacred privilege.

You are reading these words because you have a heart to care for the dying and those who grieve, whether they are family, friends, or strangers. You will discover that this guidebook will acknowledge, strengthen, and build upon what you already possess within yourself. Many of the experiential exercises and personal reflections will affirm and deepen your experience.

Although you will learn "skills" and "words" that can be used with dying and grieving persons, you will find that one of the greatest gifts you can offer another is your spiritual presence, unencumbered by prejudice, judgment, beliefs and opinions. Your caring presence allows a dying person to attend to whatever is most valuable and to die on his/her own terms, accepted and loved. You will learn there is no need to control the direction or timing of another's death, but rather to provide sanctuary so the dying may be truly supported in the transition between life and death. Similarly, you will learn that you cannot "fix" the pain caused by grief. Instead, you will find ways to be a comforting presence in the face of pain and distress. Each person's journey is unique.

Many of us have been raised to demonstrate love and compassion through acts of service and charity. The dying challenge us to serve in new ways, where there may be little physical evidence of our caring. Feeling comfortable with death and bereavement requires a willingness to enter into one's own fears, particularly fears associated with loss and control. Although there will be many opportunities for active caring and verbal exchange, there will be times when very little can be said or done outwardly.

Although death takes away every aspect of humanness, marked by roles, identity, and relationships, it challenges us to reframe experience toward more spiritual ways of being and knowing. Becoming intimate with death makes us acutely aware of our own mortality and the impermanence of life. Through our awareness of death, we can embrace life more fully.

Awareness of death is "life-changing" for the dying and for all those who encounter it. Both the dying and grieving processes challenge us to reframe our experience toward more spiritual ways of being and knowing. They can provide opportunity for:

- Authentic and meaningful relationship
- Inner exploration for the dying and the witnesses
- Inner exploration for the survivors
- Reflection about life's meaning and purpose
- Completion of unfinished business
- Spiritual and personal transformation

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Care of the Bereaved

INTRODUCTION

OUR GOALS

- To help individuals gain comfort, knowledge, and skills so they can better care for dying persons, their loved ones, and those who grieve.

- To help faith-based communities develop compassionate and skilled ministries for the dying and the bereaved through the provision of training and ongoing support to laity, faith leaders, and volunteer caregivers.

- To encourage lay people to look to their clergy or spiritual leaders for guidance in offering care within the framework of their faith tradition.

- To increase spiritually and culturally appropriate resources for the dying and the bereaved.

ABOUT THIS GUIDEBOOK

The Complete Life is designed to help support those who are called to provide compassionate care to others at the end of life and in bereavement. Through the use of discussion, stories, and experiential exercises, participants are guided in deeper exploration and understanding of dying, death, and the grieving process.

This guidebook was developed as part of a larger effort to improve end-of-life care in Hawaii, sponsored by the Kokua Mau coalition under the leadership of the Executive Office on Aging, the Hawaiian Islands Hospice Organization, the St. Francis Center for Healthcare Ethics, and the University of Hawaii Center on Aging.

Work by the U.H. Center on Aging strives to engage faith communities in improving end-of-life care and to help equip individuals to minister to the dying and the bereaved. Earlier studies conducted by the Center found that many congregations wanted to learn more about end-of-life issues, but that the topic was not easily broached. By placing end-of-life discussion in the broader context of aging, caregiving, and ministry to the sick and dying within a faith perspective, an easier introduction to these issues is possible.

Although many cultures value caring for aging family members at home, few individuals have the comfort, knowledge, and skills to provide care at the end-of-life. The Complete Life proposes to provide this training, to help develop a compassionate and skilled ministry for the dying and bereaved, and to increase spiritually and culturally appropriate resources for the dying and the bereaved.

MODULES AND LEARNING OBJECTIVES

This guidebook is divided into 2 sections, each with learning objectives:

SECTION 1 – CARE OF THE DYING

1. To understand what happens to the body as a person dies and to learn ways to make a dying person feel more comfortable.

2. To assess pain and to advocate for its control and management.

3. To know what to do when death occurs.

4. To learn about medical procedures to save and prolong life and to understand how our beliefs and values may influence our choices about these treatments at the end of life.

5. To explore ways to talk about your end-of-life wishes with others.

6. To describe spiritual care in term of values that are common to most faith traditions.

7. To explain the term "mindful presence" and to practice it while addressing spiritual needs at the end of life.

8. To gain understanding of cultural themes that may influence end-of-life choices.

9. To demonstrate the use of observation, open-ended questions, and silence to learn how to best help the dying and their families.

10. To assist the dying person and his/her loved ones in "saying good-bye."

SECTION 2 – CARE OF THE BEREAVED

1. To recognize the common physical and emotional responses to grief.

2. To understand the grieving process in terms of feelings and tasks that commonly face the bereaved over the 2 years following the death of a loved one.

3. To distinguish between normal and complicated grieving and to recognize when to seek help for the bereaved person.

4. To understand the power of a meaningful funeral or memorial service by planning your own.

5. To understand how funeral and burials are financed and the value of planning ahead.

6. To identify documents required after the death of a loved one and how to organize them in advance for others to find easily.

7. To explore ways in which different religious and cultural groups mourn their dead.

8. To recognize "difficult" deaths and to discuss how religious and cultural beliefs might influence one's ability to help the survivor.

9. To identify and understand the 5 steps to having a Compassionate Conversation.

GENERAL INSTRUCTIONS

How Is the Guidebook Organized?
This guidebook is separated into two sections: Section 1 – Care of the Dying, and Section 2 – Care of the Bereaved. Each session begins with an educational presentation and is followed by experiential and introspective activities.

How Much Time Does the Training Take?
Each of the 17 sessions takes about 1 hour to complete, so the entire training is approximately 17 hours long. The training can be arranged in 1-hour, 3-hour, or 6-hour blocks, depending on the participants' needs and schedules. For example, the entire training may be given over 3 weekends, in weekly sessions of an hour each, or in 4 sessions each of about 4 hours. Sessions may be scheduled on weekends, after worship, around a potluck lunch or dinner, or in the evening.

Who Should Take This Training?
Program participants include family caregivers, religious and lay ministers, congregants, service providers, and community volunteers who work with the dying and the bereaved. Announce the training times in the church/temple bulletin. Post flyers on bulletin boards. If the public can attend, send a press release to the local newspapers.

Where Should It Be Held?
You can hold sessions in a Sunday school classroom, meeting room, or auditorium depending on size of the expected audience.

Useful Materials
- Liquid Crystal Display (LCD) for PowerPoint presentation
- Laptop computer for instructional use
- Flip chart and magic marker
- Pencil and paper for audience
- Name tags
- Hand-outs prepared by the speaker or duplicated from this guidebook
- Refreshments

Disclaimer

Although specific information is provided on some religious and cultural practices at the end-of-life, this guidebook is not designed for a particular cultural, ethnic, or religious group. The coordinators and supporters of The Complete Life program have attempted to provide you with basic information and suggestions for where you can learn more. This information does not replace that of your physician, health care professional, or clergy person. Neither does it constitute an endorsement of groups listed or a disapproval of groups that are not listed. In addition, things change and information may become dated or inaccurate over time.

We all recognize and celebrate the crucial role of family caregivers in our society and empower professionals to respond with increased awareness, compassion and support.

– Rosalynn Carter, Caregiver and Former First Lady

Care of the Dying

BEING WITH DYING

Transitioning from Life to Death

- *Death is the irreversible ending of life.*
- *Dying is the approach toward that end.*

The last stages of life can be very stressful for the dying person and those who attend him/her. As a witness to dying, you will observe changes that may be upsetting and unfamiliar. Learning about the dying process will help.

Many physical changes occur during the process of dying that affect the emotional, social, and spiritual aspects of a person's life. There are some patterns or commonalities of dying that are observable, although not everyone follows a predictable sequence of events or stages. Health professionals speak of "dying trajectories" that suggest how persons with specific diseases will die. For example, those with a terminal illness, such as advanced cancer, will show a steady decline toward death. Those with serious chronic illnesses may have peaks and valleys that sometimes give the impression of recovery. Sudden death gives no warning. Remember that each person's death is unique.

In this session you will learn about the common signs and symptoms seen in persons who are dying. You may observe none, some, or all of these signs and symptoms in the dying person's last days and hours on earth. You will also learn things to do that can help ease physical pain and suffering. Experts who work with the dying call this comfort care. Comfort care focuses on easing distressing symptoms and relieving suffering when a cure is no longer possible.

Each person's death is unique...Learning about the dying process will help.

Work of sight is done. Now do heart work on the pictures within you.

–Rainer Maria Rilke

COMMON SYMPTOMS AND WHAT YOU CAN DO

Withdrawal from the external world. As the end of life approaches, there is a feeling of detachment from the physical world and a loss of interest in things formerly found pleasurable. As consciousness draws inward, there is increased opportunity for inner reflection. There is a tendency to sleep more. There is less desire for verbal communication. This is the beginning of letting go of life and preparing for death.

Days or hours before death, the dying person becomes less and less responsive to voice and touch and may not awaken. Sometimes, quite unexpectedly, the person may appear well and even look as if he/she is going to recover. The person may be lucid and coherent. This does not mean that there will be recovery; the person is still dying. Use this as a "window of opportunity" to say what you need to say and have closure.

What you can do:

- Always speak gently, and identify yourself before speaking.
- Presence and touch are the key gifts you can give during this time.
- If you are not part of the family, be extra sensitive to the feelings of the dying person and his/her family. Observe cues (personal, religious or cultural) that may tell you if it is inappropriate to touch. In most cases, gentle touch is appropriate.
- Dying requires energy and focus. Try not to distract the dying person from this necessary preparation. Allow the dying person this time and do not try to bring him/her back to "reality" or force participation in your world.
- Remember that you are supporting the person to "let go."

Visions and hallucinations. Visual or auditory hallucinations are often part of the dying experience. The appearance of family members or loved ones who have died is common. These visions are considered normal. The dying may turn their focus to "another world" and talk to people or see things that others do not see. This can be unsettling, and loved ones may not know how to respond.

What you can do:

- Non-judgment and presence are critical at this time. Just be as silent and supportive as possible.
- Refrain from discounting the experience and orienting the dying person to "reality." This is their reality. Most often, these "visions" are reassuring and they comfort the dying. Rarely do they upset the dying person.
- It is important to differentiate these hallucinations from "bad dreams" that may be caused by medications or metabolic changes. Although visions of loved ones are generally comforting, "bad dreams" may frighten the dying. An adjustment in medication may correct this.

Please remember, it is what you are that heals, not what you know.

–Carl Jung

Loss of appetite. As death nears, the dying person may lose interest in food and drink. The ability to swallow becomes impaired. Loss of appetite and reduced intake are normal parts of dying.

In the early stages of dying, the dying person may prefer only soft foods and liquids. In the very last stages of life, however, they may not want any food or drink. A dying person may want to suck on ice chips or take a small amount of liquid, just to wet and freshen the mouth, which can become very dry.

In the last stages of dying, forcing food when the body says "no" may be harmful or painful to the dying person. Many dying persons will exhibit the "clenched jaw" sign as a way of saying "no". Forcing fluid may cause choking, or the dying person may aspirate liquid into the lungs, making matters worse.

It is hard for most people to respect the dying person's lack of appetite. That's because many of us equate food with caring. Family members may feel that withholding nutrition is cruel or neglectful. They may worry that they are "killing" their loved one.

It is important to remember that as the physical body is dying, the vital organs are shutting down and nourishment is no longer required to keep them functioning. This is the wisdom of dying, and the body knows exactly what to do.

What you can do:

- Refrain from giving liquids or food unless requested.
- Wet the lips and mouth with a small amount of water, ice chips, or a sponge-tipped applicator dipped in water.
- Protect lips from dryness with a protective lip balm.
- Continue to be a caring and loving presence.

Change in bowel and bladder function. The two major concerns are constipation and incontinence (loss of control over bowel and bladder functions).

Constipation may be caused by lack of mobility, pain medication, and decreased fluid intake. If left untreated, fecal impaction may occur and can become uncomfortable. Laxatives are generally needed to keep the bowels clean.

Incontinence, or loss of bowel/bladder control, is likely to be distressing to the dying person and those in attendance. In the early stages, "accidents" can occur. As death nears, the muscles in these areas relax further and contents are released. This is normal. Urine is highly concentrated and sparse and may appear tea-colored. Sometimes a urinary catheter is inserted or the dying person may wear "diapers" or briefs. This will help keep linen clean (changing linen may be more disturbing to the dying person than the catheter or the diapers).

What you can do:

- Keep affected areas clean and dry to avoid rashes or bedsores.
- Watch for signs of constipation and incontinence, and help loved ones report this to the physician or nurse.
- Talk to the physician or nurse about the advantages of reducing food and fluid in the last stages of dying.

It has taken me all the time I've had to become myself.

– Florida Scott-Maxwell

Awareness of death is the very bedrock of the path. Until you have developed this awareness, all other practices are obstructed.

–The Dalai Lama

Confusion, restlessness, and agitation. Restlessness and agitation are common. These symptoms may be caused by reduced oxygen to the brain, metabolic changes, dehydration, and pain medications. Terminal delirium is a condition that may be seen when the person is very close to death, marked by extreme restlessness and agitation. Although it may look distressing, this condition is not considered to be painful. There are medications available to control symptoms. Be aware there may be unfinished business. Dying persons may try to hold on until they feel a sense of security and completion. Persons may exhibit picking, pulling, and fidgeting behaviors. These can result from medications, metabolic changes, or decreased oxygen to the brain.

What you can do:

- Never startle the dying with bright lights, harsh tones, or abrupt movement.
- Always identify yourself; even if the dying person knows you well, he/she might not recognize you at this time.
- Use a gentle voice and reassuring touch.
- With mindful awareness, be sensitive to any cues that might signal that there is something the person wants to resolve before he/she can let go. Offer support.
- Consider the use of light massage and soothing music.
- Ask the doctor if there are any medications that might help relieve the agitation.

Changes in breathing, congestion in lungs or throat. You may observe that breathing is shallow and quickened, or slow and labored. The person may make gurgling sounds, sometimes referred to as the "death rattle." These sounds are due to the pooling of secretions and an inability to cough them up. The air passing through the mucus causes this sound. The breathing pattern most disturbing to witnesses, called Cheyne-Stokes breathing, is marked by periods of no breathing at all (up to 45 seconds), followed by deeper and more frequent respirations. These respirations are common and result from decreased oxygen supply to the vital organs and a build-up of waste products in the body. This condition is not uncomfortable or painful for the dying person, although it may be unsettling to observe. The "death rattle" and Cheyne-Stokes breathing indicate that death is near.

What you can do:

- Do not panic. This can increase any fear that may already be present for the dying person.
- Raise the head of the bed (mechanically or with pillows) to help breathing.
- If secretions are pooling in the mouth, turn the head and position the body so that gravity can drain them. Suctioning rarely helps and is not recommended.
- If appropriate, wipe out the mouth with a soft, moist cloth to cleanse excess secretions.
- Speak gently and lovingly, and use gentle reassuring touch to allay fear.
- Alert the physician or nurse if breathing is especially labored or if you notice the "death rattle" or Cheyne-Stokes breathing.

Change in skin temperature and color. As the body dies, the blood moves away from the extremities toward the vital organs. You may notice that although the extremities are cool, the abdomen is warm. You may notice changes in body temperature; the dying person may be hot one minute and cold the next. As death approaches, there may be high fever. You also may see purplish-bluish blotches and mottling on the legs, arms or on the underside of the body where blood may be collecting. As death nears, the body may appear yellowish or waxen in color.

What you can do:

- Try to keep the person as comfortable as possible.
- Use a damp, cool washcloth to cool a person who feels too hot (be alert to signs such as kicking off the blankets).
- Cover the dying person with a blanket if he/she feels too cold. Don't use electric blankets or heating pads as these may burn the skin.
- Alert the physician or nurse if you notice changes in skin color. This may be a sign that death is near.
- Using a fan to circulate air may make the person more comfortable.

The caregiver of the dying acknowledges the big, yet concentrates on the small.

–Doug Smith

POINTS TO REMEMBER

1. **You can be a caring presence throughout the dying process.** Your presence for the dying person and his/her loved ones indicates loving kindness, compassion, and willingness to provide practical help.

2. **Listen, observe, and respect.** Respect the need for the dying person to be alone. He/she may not want you to witness a diaper change. The family may want time alone, too. Be aware of people's needs, and respect their dignity.

3. **Learn.** Learn what you can about the dying person's illness and the dying process so you can provide comfort and words of assurance.

4. **Remember, you do not know how it feels to die.** Avoid the urge to say things like: "I know how you feel," "This is God's will," or "Give thanks, you've led a long, full life." Don't offer "false hope." Just listen, be compassionate, and attend the journey. If you feel a need to be consoling, just assure the dying person and his/her loved ones that they will not be abandoned, but loved and cared for until the end.

5. **Be practical.** See what needs to be done and do it. Helpful tasks may include washing clothes, changing bedding, shopping, preparing a meal, cleaning etc. This is valuable help!

6. **Realize your limitations.** No one is perfect. No one can do everything. Get help when you need it. Take a break when you need one. Encourage the dying person and his/her loved ones to call the physician or nurse with questions. Refer to the resource section of this manual for other agencies and organizations that can help.

7. **Use this opportunity for your own spiritual growth.** Use this time to enrich your own spiritual path, whether you are a primary caregiver, visitation minister, community volunteer, or friend. Whether you share a faith tradition or not, words of kindness and love are always welcome. Do not impose your faith position upon another. When offering a prayer, make certain the prayer is meaningful to the dying. Do not "pray at" but with and for the dying. Otherwise, pray from the heart in silence.

There are two ways to live your life. One is as though nothing is a miracle. The other is as though everything is a miracle.

–Albert Einstein

ACTIVITY: Case Study of Dying Person

Mr. Tom has cancer of the lung that has spread to his kidneys, bone, and brain. He has chosen to die at home rather than in the hospital. Mr. Tom has asked that no extraordinary measures be taken to prolong his life. He requests that comfort care be given.

Put yourself in the position of the caregiver and examine the following scenarios. What would you do or recommend be done in each case to make Mr. Tom more comfortable?

1. The pain medication necessary to keep Mr. Tom comfortable is causing constipation. He hasn't been able to have a bowel movement for three days. He seems to be getting more restless and agitated. What would you do?

2. You notice that Mr. Tom has been breathing through his mouth, and that his lips and mouth seem extremely dry. What would you do?

3. You enter the room and notice that Mr. Tom is speaking to someone, but no one is in the room. He seems reassured by the presence of this person. What would you do?

4. Death seems to be getting nearer. You notice that Mr. Tom is no longer responsive. His breathing seems congested and "wet," but otherwise he seems to be comfortable. What would you do?

REFLECTIONS

Remember a time when someone you loved was dying.

- *What were the circumstances?*
- *Who was there?*
- *How did you feel about being near death?*
- *What did you do to provide comfort?*
- *How did you feel inadequate?*

 Write your reflections here.

At heart, hospitality is a helping across a threshold.

–Ivan Illich

Why Do People Die in Pain?

Studies show that a large proportion of persons with advanced disease die in severe pain. There are several reasons for this:

- The disease process that is causing death may be painful.
- Interventions to prolong life or treat disease may cause pain.
- Not all health professionals are trained in pain management.
- The prescribed medications may not be working well.
- Dying persons may not want to take pain medications because they fear constipation (a common side effect) or drowsiness.
- The health care provider, family, or dying person may fear addiction. (Pain management professionals encourage us not to be concerned about addiction with any dying patient, even if he/she has an addiction history.)

We all must die.
But if I can save someone
from days of torture, that is
what I feel is my great and
ever new privilege. Pain is a
more terrible lord of
mankind than even death
itself.

–Albert Schweitzer

COMMON FEARS

Fear of addiction. The fear of becoming addicted to pain medicines, such as morphine, is common. However, addiction should not be a concern among persons who are dying and family members who care for them. Some people worry that round-the-clock dosing means that too much medicine is being taken. In reality, managing pain round-the-clock reduces the amount of pain medicine taken. This is because it helps prevent "breakthrough" pain and subsequent "rescue" doses. Round-the-clock dosing allows the dying person to carry on normal activities as long as possible. Stopping medicine abruptly because pain is better or for fear of addiction can cause the return of severe pain. Getting pain back under control can take a long time.

Belief that pain may be deserved or good. If people believe that pain is deserved, they may underreport pain or be reluctant to ask for pain relief. Others may interpret their physical pain as suffering, and refuse pain medication because they believe that suffering is related to salvation. In these cases, it may help the dying person to talk to a religious leader to clarify their faith's beliefs about physical pain, punishment, and salvation. Remember, only when physical pain is controlled can the issue of suffering truly be addressed.

A dying person may have these other fears.

- The presence of pain means my disease is getting worse.
- Treating the pain will "mask" the real problem, which could be treated.
- Taking too much medicine may kill me.
- I don't want to bother the doctor too much.
- I don't want to hurt my doctor's feelings by reporting that the pain is not controlled.

MANAGING PHYSICAL PAIN

Most physical pain can be controlled. No one should die in pain when the means to relieve it are available. All persons have the right to have their pain controlled.

Pain is real. Believe the person has pain if it is reported to you. Remember, each person is an individual and perceptions of pain differ.

Talking to the doctor. People should expect their doctors and nurses to ask these questions about pain:

- Do you have pain?
- Where is it? What does it feel like: dull, stabbing, throbbing, etc.?
- How intense is the pain? Please rate it on a scale from 0 to 10, with 10 being the worst pain you've ever had.
- What makes the pain better or worse?

The answers to these questions will help the doctor prescribe the right medicine in the right amount. Before the conversation is over, make sure that the dying person and his/her caregivers understand:

- What may be causing the pain
- The recommended treatment
- The possible side effects
- What to do if there are questions or concerns

I aspire only to relieve the pain and suffering of others, and I trust in doing so, I may understand more clearly Your nature.

–St. Francis of Assisi

Getting the most from pain medicines. Medicines should be given by the least invasive route, usually by mouth in either pill or liquid form. Sometimes a "patch" is placed on the skin. For optimal pain relief, medicines should be scheduled round-the-clock. This helps to keep pain under control and reduces "breakthrough" pain and the memory of pain.

- Oral doses take effect in about 45 to 60 minutes and are at maximum strength at 90 to 120 minutes. To quicken absorption and pain relief, have the person lie on his/her right side. The medicine is absorbed in the small intestine, not in the stomach.
- Skin (transdermal) patches for pain take 12 hours to be at full strength and last for up to three days. Duragesic (Fentanyl) patches commonly are used to control pain.
- The rectal route is commonly used to administer medications (suppositories). Their absorption rate is similar to oral medications. Pain medicines also can be given under the tongue (sublingual), under the upper lip, between the teeth and gums (buccal), or vaginally. These are called transmucosal routes.
- If pain medications cannot be given orally or rectally, they can be given intravenously (IV) or by subcutaneous injection. IV medications take effect rapidly, in about 5 to 10 minutes.
- Pain medicines by intramuscular (IM) injection take effect in 15 to 30 minutes. IM medications should generally be avoided in dying patients. Injections can be painful and may damage tissues and nerves. Lack of muscle tissue to administer the injection as the person loses weight is also a concern. Finally, the injection site must be rotated, increasing disruption to the patient.

Different medications for different kinds of pain. There are different approaches to pain control, depending on the kind of pain.

Mild pain is usually treated with pain medicines taken every 3 to 4 hours. Regular dosing of any pain medicine is very important. If medicines are not given properly, the person's pain may get out of control. This may be difficult for caregivers at home who must wake up to give doses of short-acting medication around-the-clock.

For **severe pain**, long-acting medicines do a much better job. Many are taken every 12 hours, which means the dying person and caregiver don't have to wake up for pills in the middle of the night. Steroids, antidepressants, anti-emetics (for nausea), anti-anxiety agents, or other medicines may be given in addition to pain medicine.

"Breakthrough" pain is pain that occurs intermittently. It is sometimes related to activity and sometimes occurs unpredictably. It is best for the patient to take short-acting pain medications the moment the breakthrough pain starts. If a person is taking breakthrough-pain medication frequently, the long-acting pain medications may need to be increased. Taking frequent doses of breakthrough-pain medications is not an indication of addiction, but an indication that the pain has become more severe and/or the disease has progressed. In general, the goal is to prevent pain rather than to chase pain.

Keeping track of pain and pain medication. Caregivers should keep a list of the type and amounts of each pain medicine taken, the times given, and the pain ratings (on a scale from 0 to 10). This information should be shared with the physician or nurse. If too many "rescue" doses are needed, this may indicate the need for a higher round-the-clock dose. It does not mean the person is becoming addicted.

COMMON SIDE EFFECTS

Constipation. Laxatives and stool softeners are generally prescribed to relieve constipation.

Dry mouth. If the person can take liquids by mouth, you can help keep the mouth moist with sips of water or ice chips. Sucking on hard candies also can be helpful.

It is not death, it is dying which alarms me.

– Michel de Montaigne

Nausea and vomiting. Anti-emetics may be prescribed to reduce nausea and vomiting. These medicines may cause drowsiness.

Confusion and disorientation. Talk to the physician about trying another pain medication if the dying person wishes to be more alert and oriented. Although our goal should be "zero pain at life's end," some people want to stay alert until the end and are willing to put up with some pain.

Drowsiness and dizziness. Initially, there may be drowsiness or dizziness. These symptoms gradually improve after a few days.

Respiratory depression. Although respiratory depression is a common fear with strong pain medicines, if the medications are taken as instructed, this will not occur.

Itching. Itching occurs more commonly with natural opiates, such as morphine, and less commonly with synthetic pain medicines. This bothersome symptom can be controlled with medications and typically improves as pain management continues.

HELPING OTHERS MANAGE PAIN

Families and loved ones can help doctors by assessing pain at home through skilled observation and asking the right questions. Here's what to do:

ASK

- Do you have pain? Where is it? What makes it worse or better?
- If pain is present, please rate it on a scale of 0 to 10, with 10 being the worst pain you've ever had.
- What do you think is causing the pain?
- Do you think the pain means that you are getting worse?
- Do you feel that pain is an expected part of dying?
- Do you feel that the medicine is helping you?

OBSERVE

- Is the person reluctant to take pain medicine?
- Does the person have fears about addiction?
- Are there cultural or religious barriers that might prevent the person from reporting pain or taking medication to manage it?
- Are there other methods of pain management that might be appropriate to his/her culture?
- Are there economic barriers, such as lack of health care insurance or drug coverage?
- Does the current pain medicine seem to be working?

BELIEVE

- Believe the person has pain if it is reported to you.
- Do not downplay or discount the reality of another person's pain.
- Remember, every person's perception of pain differs.

ACT

- Advocate on the person's behalf. If you are not a family member, speak to them sensitively about your concerns. Encourage them to voice their concerns to the doctor or to request someone who specializes in pain management to assist, such as someone from hospice.
- Suggest other appropriate resources that can help. Some dying people find relief through acupuncture, healing touch, massage, and other complementary therapies.

POINTS TO REMEMBER

1. Pain is a physical feeling. Suffering is the enduring of pain or unresolved circumstances, perceived or real. Suffering may occur on different levels—emotional, mental, spiritual, or even socio-economic.

2. The goal of good pain management is three-fold:
   - Minimize physical pain.
   - Treat the side effects of pain medicines.
   - Recognize and offer relief for suffering.

3 Ask for help before pain becomes severe. Pain is easier to control when it is mild.

4. Learn how to assess and describe pain. This will make it easier for the physician to prescribe the right type and amount of pain medication.

5. Pain medication should be taken as prescribed, even if it means taking it round-the-clock.

6. Getting pain under control requires frequent reassessment and may mean changing doses, drugs, and routes to achieve optimal results.

7. Pain is an energy-drain. Chronic, continuous pain can be exhausting and can limit activities. Have patience and don't hurry activities.

8. Complementary therapies, including traditional healing, may be helpful and may include:

   - Healing Touch
   - Guided Imagery
   - Rhythmic Breathing
   - Humor
   - Aroma Therapy
   - Acupuncture and Acupressure
   - Massage
   - Art and Music Therapy
   - Hypnosis
   - Essential Oils

ACTIVITY: Relieving suffering

A common concern of caring communities is to be aware and responsive to the needs of its members. Yet, often the pain and suffering of others goes unnoticed. We may feel unskilled in responding to another's pain.

Break into groups of 3 and select one of the cases below. One person in the group should take the role of the person in pain, another is the "friend" (caregiver, visitation minister, etc.), and the third is an observer who will give feedback on the interaction.

• Marie, a 76-year-old member of your congregation, is dying from cancer. She has told you that she believes her cancer is "God's will for her life" and that she accepts her suffering. She says she has not led a good life, and she is getting what she deserves. What would you say or do?

• Mark has a painful, chronic illness that will lead to death within four months. He has a great deal of physical pain, so much so that some days he does not leave his home. Mark's only brother is a drug addict, and Mark refuses to ask for stronger pain relief because he does not want to get addicted. What would you say or do?

• Sara has always been demanding and self-centered. She tends to over-exaggerate most situations. Recently, she was diagnosed with liver cancer. During a home visit, she tells you how hard this has been on her emotionally. She tells you that the pain is severe and unrelenting. When you ask what she has been taking for pain, she takes out five different medicines, two of which are strong narcotics. You can't imagine how anyone taking all this medicine could still be in pain. What would you say or do?

Other questions for discussion:

1. How can you best advocate for someone who is in pain?
2. How can your faith community develop or strengthen its ministry to the sick and dying?

REFLECTIONS

As we become more aware of what causes our own suffering, we become more sensitive to the suffering of others. In understanding the nature of suffering, we can open our hearts toward others and demonstrate care with love and compassion. In this session we discussed the difference between pain and suffering. Pain is a feeling and suffering is the "whole person response" to the sensation of pain. Reflect upon the difference between pain and suffering by remembering a time you were in physical pain.

- *What was the cause of the pain?*
- *What meaning did you give to the pain? Was there a message for you in the pain? What was it?*
- *How did it affect or change your life?*
- *Did you suffer because of the pain? Did you feel angry, isolated, sad, or self-critical? Were you afraid?*
- *Did you notice a difference between the sensation of pain and your response to it? How much of your distress was caused by your reaction to the pain as opposed to the pain itself?*

The next time you have pain, see if you can distinguish between the actual sensation of pain and your reaction to it. Does the nature of the pain change when you lessen your reaction to it? Does your suffering increase or decrease when meaning is given to the sensation of pain?

 Write your reflections here.

WHAT TO DO WHEN DEATH OCCURS

Most people in this country die in hospitals or in institutional settings, even though the majority of Americans want to die at home. Many people die alone. We welcome a life into the world with joy and celebration, but often turn our backs on the passage from life to death, feeling unequipped to be a midwife of dying and unfamiliar with what to do after death occurs.

Our hope is that fewer people will die alone. Rather, dying people deserve to:

- Be surrounded by loved ones
- Have spiritual support at life's end
- Be relatively free from pain
- Die in the setting of their choice, whether at home or in an institution

When death finally occurs, caregivers and loved ones face a number of realities and tasks. This section gives information on what to do immediately following the death.

For the raindrop, joy is entering the river.

– The Sufi prophet Ghalib

Death As Reality

As expected as someone's death may be, it still feels unreal. It takes time for the reality of death to sink in. If the person dies in a hospital, the family may be asked to leave when death is near. After death occurs, the body may be removed quickly. The family may feel a sense of being "banished" or "displaced." Even in an institutional setting, however, you have the right to stay near the body and take time for closure so that the death seems more real and less of an illusion. This is the first step in accepting the reality of death.

What Can We Do Immediately After the Death?

Holding or touching a loved one who has died, or praying, crying and sharing stories during this time can be a powerful step toward healthy grieving. Grieving can be a communal experience rather than an isolated event.

Many people want some kind of religious attendance or reassurance when a loved one dies. A clergy person can be called to bless the deceased and/or lead the family in prayer. Faith communities are vital resources that can ensure sacred handling of the dead and compassionate care of the grieving.

Who Do We Notify?

The answer to this question depends on the place and circumstances of the death:

- If the death was unattended and unexpected, the police must be notified.
- If the death occurs at home and is expected, there is no need to call anyone immediately. If the dying person is a hospice or home health client, the on-call nurse will come to the home and confirm that death has occurred. Otherwise, call the physician. If you call 911, remember that emergency procedures will be initiated, even if you know that the person is dead.
- If the death occurs in an institutional setting, the doctor will pronounce the death and inform the family.
- A designated family member will usually notify friends and other significant persons of the death. This does not have to be done immediately.

The Death Certificate

The family doctor or medical examiner will supply and must sign the Death Certificate within 24 hours, stating the cause of death. The rest of the form must be completed in black ink or typewritten. The Death Certificate must be filed with the local registrar within 3 days and before final disposition of the body. States may differ, so check with your local Department of Health.

The survivors should have 10 to 12 copies of the Death Certificate on hand as documentation of the death. These are needed to verify the death later on when applying for insurance benefits and attending to practical/legal matters. Generally, the certificate may be obtained through mail or in person at the Vital Statistics Branch of the Department of Health or through most funeral homes.

When Do We Call the Mortuary?

After the family and loved ones have had adequate time to say good-bye, it is time to call the mortuary. This does not have to be done immediately. Mortuaries are on-call 24 hours a day. Generally, the mortuary will come to receive and transport the body.

Death, like birth, is a secret of Nature.

–Marcus Aurelius Antoninus

ACTIVITY: Group Discussion

Break into groups of 2 or 3. Take turns talking about the following questions. If you feel comfortable, share your observations and insights with the entire group.

Reflect upon a time when someone you know died.

- In which type of setting did the death occur?
- Describe what happened.
- Were there sights, smells, or sounds associated with the death?
- Are the memories positive or painful ones?
- What was your role?
- What might have been improved?

REFLECTIONS

- *Where would you want to die? Why?*
- *Who would you want to be there?*
- *Would you choose to be buried or cremated? Why?*

 Write your reflections here.

PLANNING AHEAD: Advance Directives

Although we would like to think that we will always be healthy and able to make decisions for ourselves, we never know when a sudden illness or serious condition might arise, making us unable to do so. Making your wishes known while you are still healthy is a good idea. Your family and loved ones will benefit from advance planning. It will help relieve them of the uncertainty and burden of making medical decisions for you in the event that you become incapacitated.

Planning in advance for health care decisions is the best way to make sure your voice is heard and your wishes are respected.

Your Advance Directive

An advance directive is a written or spoken statement about your future medical care. The advance directive lets your doctor, family, and other people know how you want to be treated if you become seriously ill and cannot tell them. Planning in advance for health care decisions is the best way to make sure your voice is heard and your wishes are respected.

In your advance directive, you may share your wishes about:

- The kind of medical treatment you want or don't want
- The person you want to make health care decisions for you when you cannot
- What you wish to have for comfort care
- Ethical, religious, and spiritual instructions
- Anything else about the end of your life that you want your loved ones and your health care providers to know

BENEFITS OF ADVANCE DIRECTIVES

They Help People Know What to Do

Your written advance directive is a gift to your family members and friends. By documenting your wishes, others won't have to guess what you want if you can no longer speak for yourself. Discussing your choices now can help. If even one family member disagrees, it will be difficult for your doctor to honor your wishes. An advance directive is the best means to make sure that your wishes are carried out. Even if you currently have a living will, check with your state to see if there have been updates to the law. Many states have adopted new laws that give you more choices.

Health Care Decisions Will Not Be Left to Chance

You make choices every day – about where you want to live, who you want to marry, your work, your home, and your life. Why let health care decisions be left to chance? Now is the time to decide about the kind of care you want while you can still make your own decisions and have time to talk about them with your family and doctors.

They Let Others Know Your Values

Advanced technology makes it possible for patients with little or no hope of recovery to be kept alive for months or even years. That has made it more important for people to express how they feel and what kind of care they would want if they were unable to make their own decisions.

Advance Directives May Include Spiritual Instruction

You may also use your advance directive for ethical, religious, and spiritual instructions. Many of our communities and families are multi-ethnic and may have differing spiritual traditions. Let your loved ones know what practices will ease the transition at the end of life.

TALK ABOUT IT

Talking Now Is a Gift You Give to Those Close to You

In the event that you become so ill that you can no longer speak for yourself, advance planning will help those close to you make the decisions you would want. Surviving family members of persons who did not have an advance directive tell us that they agonized over their decisions and always wondered whether they did the right thing.

Use an Example of Someone You Know

It is often easier to start by talking about someone else's experience. You could describe the experience someone you know had at the end of his/her life. For example, you could ask:

- "Do you remember when our neighbor was in the hospital before she died?"
- "What did you think about the care she received?"

Then share what you would want if you were ever in this condition. Or ask your family members what they would want. Enlist the help of your family or loved ones in making sure that if this happens to you, they will respect your wishes. It is also important to discuss your concerns and wishes with your doctor and minister.

Getting Help

Sometimes you may need the help of a friend, counselor, social worker, or clergy person to start talking with your family about the end of life. There are people from all walks of life and religious groups who have the experience to help.

Questions to Ask Your Doctor

While you are still healthy, it is good to review your end-of-life concerns and wishes with your doctor.

Should you or a loved one become seriously ill, here are some possible questions for your doctor:

1. Is there a possibility I will be well again?
2. If there is no cure for my illness, can I still improve?
3. What can I expect in the next weeks and months ahead?
4. How long do other people with my condition live?
5. Are there any treatments that will make me well again?
6. Are there any treatments that can help me to live longer?
7. If these treatments prolong my life, will they make me feel worse?
8. Is comfort care the best choice for me now?
9. Which kinds of care will I receive if I choose comfort care only?
10. What other help is available for me and my family or loved ones at this time?

Think about the kind of treatment you want, and talk about it with your loved ones and your health care provider. Talking about these issues may not be easy; there may be resistance. Many people, including some doctors, are uncomfortable talking about living at the end of life. The exercise in this session will offer suggestions for starting that conversation.

Even though oral instructions regarding your health care are considered legal, it is best to write down your wishes. Make sure you give copies to your family members, your doctor, and your clergy person or temple leader. Be prepared to bring a copy with you if you are hospitalized. Most hospitals will ask you if you have an advance directive when you are admitted. Do not leave copies in a safe deposit box where they will be found too late to do any good.

UNDERSTANDING LIFE SUSTAINING TREATMENTS

The following are examples of some of the common medical treatments used to extend or sustain life in terminal conditions. Always discuss the risks and benefits of all surgeries and other medical treatment decisions with your doctor, and include your minister when discussing difficult decisions that involve your faith.

The first duty of love is to listen.

–Paul Tillich

Cardiopulmonary Resuscitation (CPR)

Normally, when someone suffers a cardiac arrest or heart attack, a "code" is called, and cardiopulmonary resuscitation (CPR) is initiated. The heart is "jump-started" with an electrical impulse, and manual compressions are administered to the chest in an effort to restore it to its normal rhythm. In a hospital or health care facility, unless there is a written order not to resuscitate, CPR will be given. If cardiac arrest occurs and 911 is called, CPR will always be initiated. Those who receive CPR are often put on mechanical ventilators, or breathing machines.

Mechanical Ventilation

When people can no longer breathe for themselves and wish to have their lives prolonged, they are "vented" or placed on mechanical ventilators. These are machines that breathe for them, forcing air into the lungs. In emergency situations, such as cardiac arrest, mechanical ventilation is common. Persons who are "brain dead" can no longer breathe for themselves and can be kept physically alive only through mechanical ventilation. Once initiated, withdrawal of mechanical ventilation is usually a difficult decision for family members. Legally, withdrawing a ventilator is not murder. Just because it is started does not mean it must be continued.

Blood Transfusion

This includes whole blood or blood products. Some people do not want whole blood, but will accept plasma. There comes a point at which blood transfusions no longer improve the quality of the terminally ill person's life.

Surgery

Before a surgery is considered, one should understand the risks and benefits of the surgery. Will it provide comfort and relieve suffering, or merely extend life? Are there other, less invasive procedures that can increase comfort and reduce pain? In terminal conditions, some surgical procedures are performed to reduce pain and increase comfort and are not meant to be curative.

Radiation

Radiation is often used in persons with cancer. The use of radiation or radioactive material can be helpful in reducing bone pain and inhibiting the growth of tumors. Swelling and inflammation around the site receiving radiation are common. Some side effects of radiation can be immediate. Others may occur months after treatment.

Nutrition (Food) and Hydration (Fluids)

Advance directives commonly include instructions to administer or withhold life-sustaining treatments such as artificial nutrition (food) and hydration (fluids). Unless people state their wishes not to have artificial nutrition and hydration in a terminal condition, they will generally receive them. Even when a dying person has capacity to eat and drink, he/she may choose not to. Forcing food when a person is dying and not hungry can increase pain, result in aspiration (choking), and worsen the condition. Forcing fluids may make the situation far worse by causing breathlessness, edema (swelling), ascites (swelling of the abdomen), nausea, and/or vomiting. The main purpose of food in terminal illness is enjoyment, not nutrition. Intravenous (IV) hydration is inappropriate for someone who is close to death. At this time, many organ systems in the body are not functioning well. The extra fluid imposed on the body at this time can produce swelling, increase difficulty breathing, cause more frequent urination, and add pressure upon tumors. In general, a person who is near death will have more discomfort on IV fluids. Research indicates that dehydration during the last days and hours of life can be protective. The body's release of natural pain-relieving hormones helps to promote a more peaceful death.

Antibiotics

Antibiotics have become a cornerstone of modern medicine. They are commonly given to treat many different infections. However, the use of antibiotics should be carefully considered in terminal conditions. For example, pneumonia used to be called "the old person's friend." Today, it can be effectively treated. But if a person is close to death, is this the best thing to do? Always ask your doctor about the risks and the benefits of this or any other medical intervention.

Questions to Ask When Considering Medical Interventions

- Which problem or symptom would this treatment or procedure address?
- What is involved?
- What are the side effects?
- What will happen if the treatment or procedure is not done?
- What are the benefits and the risks?
- Will the treatment or procedure improve the quality of life or merely prolong it?

ACTIVITY: Starting the Conversation*

Conversations about end-of-life issues are not easy, particularly with family members and loved ones. Family members may not agree with our wishes and abruptly end conversations. Denial of death is common. Yet these are conversations we must have if we are going to get the care and respect we want at life's end. Break into pairs if space allows, or have 2 people read one of the following 2 scripts aloud for the group.

Script 1: Penny and Beth

Penny: Honey, can I talk to you for a few minutes?

Beth: Sure, Mom.

Penny: You know I haven't been feeling very well lately. The doctor just called, and she says my latest blood tests look suspicious. Given my symptoms and all, she thinks I may have cancer. Just in case that's true, we need to talk about what I want if I get so sick I can't do things for myself. I might not even be able to think straight. You're the only person I have in my life right now.

Beth: Don't talk like that Mom. Gee, you don't know for sure, right? I'm sure it's nothing. They make mistakes all the time about these things. Listen, I'm late for work. We can talk about this another time. OK?

Penny: I really need your help right now. I want you to know what to do in case things get bad quickly. I know we haven't talked about this before and we should have, a long time ago. Please, I don't want this to be any harder than it already is.

Beth: You're overreacting. After all, you don't know definitely if you even have cancer. I'm certain there's nothing to worry about. You're going to be around for a long time. I really have to go now. Bye.

Questions for Discussion:

- Do you think similar conversations are typical in most families?
- What do you think Penny might have wanted to say to her daughter?
- How did you feel about the daughter's reaction?
- If you were Penny, how would you begin the conversation next time? Or would you?

** (Adapted from Talking it Over: A guide for group discussions on end-of-life decisions California Coalition for Compassionate Care, 1999).*

Script 2: Bob and Kara

Kara: That must have been a really hard decision for Marcia's family to stop treatment. She's suffered so long and struggled to stay alive. We all thought she'd beat the odds. I guess they don't think there's hope anymore.

Bob: I think it must have been a very hard decision for them. Before she stopped communicating, she told them all she didn't want her life prolonged if nothing more could be done. I guess that made it easier.

Kara: There must have been something the doctors could have done! Modern technology right? They can do almost anything these days.

Bob: I think they tried everything they thought might have been helpful. She just wasn't going to get better.

Kara: The family shouldn't have made that decision for her this soon. They're not giving her a chance to fight! She can't even speak for herself. Maybe she changed her mind.

Bob: You sound pretty angry about this.

Kara: I am! I can't believe they could do that. I don't think they did the right thing. She is such a fighter. Did anyone see her wishes in writing? How can they be sure?

Bob: Marcia let her doctor and everyone close to her know what her wishes were before she got sick. No tubes, no life support. Her family was just honoring her wishes. Maybe it's time for us to talk about what we would want if something like this happened to either one of us. It sounds like we have very different opinions about it. What if I had to make that decision for you? Or you for me?

Questions for Discussion:

- Would it be difficult for you to have this conversation? Why?
- Which person can you relate to, Kara or Bob? Why?
- What would you do if your family or loved ones disagreed with your wishes?
- Has anyone you know been in a situation like this?

REFLECTIONS

- *Is it difficult for you to have conversations about this topic with your family?*
- *What would need to happen to make this easier?*
- *Have you or your family members completed an advance directive?*
- *Does everyone in your family know what your wishes are?*
- *If you were to make a decision for your parent, spouse, partner or child, would you know what to do?*
- *If you were in a coma tomorrow, would your family know what to do?*

 Write your reflections here.

SPIRITUAL FOUNDATIONS OF COMPASSIONATE CARE

Most faiths teach that human death is not final, but a transition point leading to another form or realm of existence. Dying is seen as a natural part of life and is expected. People of faith generally have more acceptance of death, seeing life as an opportunity for spiritual growth and a preparation for death.

It is only with the heart that one can see rightly; what is essential is invisible to the eye.

–Antoine de Saint-Exupery

The prayers, rites, and rituals of our faith traditions serve several functions:

- They can help to comfort the dying and their loved ones.
- They can affirm our faith.
- They can ease the transition between life and death.
- They allow for a kindred spiritual connection between 2 or more people.

What Is Spiritual Care?

Spiritual care encompasses values that are common to many faith traditions. These include the sanctity of life, love and compassion, forgiveness and reconciliation, service to others, and meaning. Faith-in-action is often demonstrated by caring for those who are suffering.

Who Can Provide Spiritual Care?

Anyone who is mindfully present for another, demonstrates love, embodies compassion, and refrains from judgment can provide spiritual care. Lay caregivers should look to their traditions and seek help from clergy to learn more about providing spiritual care.

Spiritual Care Honors the Sanctity of Life

Most faiths affirm human life as a gift and a sacred trust. We are asked to use our bodies responsibly while we are alive. Yet human life will end and thus is placed in a context of impermanence, marked by the inevitability of suffering. Death teaches us about the sanctity of life.

Most faiths teach that human death does not extinguish spiritual existence. Instead we understand that one's spirit or divine nature continues beyond death. Thus, in providing spiritual care, we can:

- Acknowledge the mystery of life and death.
- Affirm the permanence of the spirit, despite the impermanence of the body.
- Understand the interconnectedness of all things.

Compassion is the ability to see how it all is.

– *Ram Dass*

Spiritual Care Involves Love and Compassion

Most faiths talk about the importance of loving one another and showing compassion. What do these 2 words mean in terms of spiritual care? According to Webster's dictionary:

Love is the benevolent concern for the good of another.

Compassion is the sympathetic consciousness of another's distress, together with a desire to alleviate it.

When faith families lend compassionate care and support to one another in the journey of living and dying, they afford an opportunity to penetrate the mystery of death and glimpse what lies beyond.

Thus, in providing spiritual care we can:

- Show benevolent concern for the dying person and his/her loved ones.
- Acknowledge the distress that he/she may be experiencing.
- Ask what might be done to help alleviate that distress.
- Accept the dying person as he/she is.
- Refrain from passing judgement.

Spiritual Care Involves Forgiveness and Reconciliation

Forgiveness and reconciliation are prominent factors in the provision of spiritual care to the dying. Forgiveness allows the dying person and his/her loved ones to "let go" of past hurts and immediate circumstances. This may include forgiveness of family members as well as forgiveness of medical systems that are unable to cure the dying person.

Forgiving oneself may be the most difficult challenge facing the dying person and his/her loved ones. Not living up to standards or expectations placed upon oneself can feel burdensome and prevent resolution of deeper issues.

Work is love made visible.

–Kahlil Gibran

Without forgiveness and reconciliation, the transition from life to death may be even more difficult. When forgiveness and reconciliation are possible, they may foster deep healing and help pave the way toward an easier death.

Thus, in providing spiritual care, we can:

- Validate the dying person's desire to forgive others or seek forgiveness from another, if he/she discusses it with you.
- Assist the dying person if he/she asks for help in resolving past problems.
- Acknowledge God's love for all people.
- Acknowledge that humans are imperfect.

Spiritual Care Involves Service to Others

Dying is not easy for the dying person or his/her loved ones. Spiritual care carries the potential to decrease suffering through your service. For example, the dying person may need you to listen in order to make sense of this transition. He/she may want to reminisce about the past or need you to write letters. A simple foot massage or a reading from a favorite book may be appreciated.

The suffering of loved ones can also be decreased through your service. Family members may appreciate your help with housekeeping, shopping, or food preparation, while they attend to the dying person. They may want you to be with their loved one while they take a break or attend to other business.

Thus, in providing spiritual care we can:

- Acknowledge that people need to help each other throughout life.
- Ask what can be done for the dying person. Sometimes, a dying person may want you to do something, or may just want you to listen or to be together in silence.
- Extend help to family members and significant loved ones.
- Remember that all tasks are important.
- Understand that service is its own reward.

Spiritual Care Helps People Find Meaning

People of faith look to their traditions for guidance, direction, and sanctuary. Faith communities can provide a safe place to express fears and concerns about life. Most people who are dying want to know that their lives had meaning and purpose. As spiritual caregivers, we can help facilitate this process.

As we assist others in moving toward a fuller and more meaningful life, we discover the same for ourselves. When we share the dying process with another, we come closer to the higher power or divine nature of our faith.

Thus, in providing spiritual care we can:

- Offer to listen as the dying person describes the meaning and purpose of his/her life.
- Validate positive thoughts and feelings the dying person may express.
- Affirm the beauty of the universe and the dying person's important contributions to that beauty.
- Refrain from passing judgment.
- Refrain from telling your own story. Your best support might be to just listen.

Everyone can love in the place where they are. We can all add our share of love without leaving the room.

–Helen Nearing

STICKY ISSUES

Caring for People Who Want to Hasten Death

Some persons may want to hasten their deaths because of intense suffering, and they may ask you for assistance. Affirming and enhancing the quality of life until death should be the goal of care. Allow the person to live and die with dignity and respect. Make sure that pain is managed properly. If a death occurs by suicide or drug overdose, refrain from passing judgment or placing guilt on surviving family members, regardless of your beliefs about this. This is neither responsible nor compassionate.

Caring for People Who May Not Share Your Depth of Faith

Allow those who are dying to describe the depth of their faith. Some people may not want to delve deeply into spiritual issues. The limits set by the dying person should be respected at all times.

Spiritual vs. Religious Care

Spiritual care is not necessarily religious care, but religious care is most often a part of spiritual care. As death nears, persons may now question their faith and feel that they are spiritually abandoned, rejected, or even punished by God. What once had meaning may now seem empty. The deeper questions that arise during this time are difficult to answer. For example, some dying people may ask, "How could a loving God let this happen to me?" As a spiritual caregiver, you should not attempt to answer this question. If the person has already requested to be cared for by a particular religious group or person, it may be helpful to contact the person they have designated for their religious care at this time.

Spiritual care, therefore, is less about having answers and more about being genuine and present in each moment for the dying person. Compassion, listening from the heart, gentleness, loving kindness, and mindful presence form the cradle of spiritual care and help to ease the transition between life and death.

ACTIVITY: Religious vs. Spiritual Care

Case example

Mrs. Miller, an 84-year-old widow, was diagnosed with cancer of the bladder five years ago. Over those past 5 years, she has undergone extensive treatment, which included outpatient surgery, chemotherapy, and radiation, with good results. Last year, the cancer spread to her right kidney. The doctor recommended surgery before the cancer spread to other organs in the body. Mrs. Miller agreed. She was a strong Christian and active member of a wealthy 5,000-member church. She expected spiritual care and visitation during her stay at the hospital, as she had told her friends at church she would be having surgery the following week. The surgery was successful. Unfortunately, Mrs. Miller developed serious complications that placed her in critical condition. As her life lay in the balance, no one came to provide spiritual care. A week passed, and still no one from the church had come to visit. Mrs. Miller grew increasingly despondent and in need of spiritual care. She questioned the meaning of her life and felt abandoned by God and her church family. Finally, a minister came to visit, stood over her, recited a prayer at the bedside, and left.

Discussion

1. Do you feel that people should have to "ask" for spiritual care?
2. What more could Mrs. Miller have done to improve communication with her church family?
3. How could this problem be prevented in the future?
4. If you were Mrs. Miller, how would you have felt in this situation? Which kind of spiritual or religious care would you want to receive?
5. Do you feel the minister provided spiritual care, religious care, or both?
6. What more could the minister have done?

REFLECTIONS

- *What does spiritual suffering mean to you? Have you experienced it?*
- *How do you identify spiritual suffering in others? How does your faith community respond to it?*
- *Do you believe that suffering is necessary for spiritual growth?*
- *Which kind of religious and/or spiritual care would you like to receive at the end of your life? Why?*


Write your reflections here.

CULTURAL BELIEFS IN DEATH AND DYING

The World Grows Smaller

Today, many of us live in communities made up of multiple ethnic groups. Interethnic marriage is common. Churches and temples often have multi-ethnic congregations. We enjoy learning about and sharing in each other's cultural traditions.

Cultural Beliefs That Impact Death and Dying

Different cultures have different beliefs and customs that may affect their practices related to death and dying. Some of the beliefs are described here.

Perhaps the shortest and most powerful prayer in the human language is help.

–Father Thomas Keating

Filial Piety

Filial piety refers to the loyalty and devotion of children toward their parents. In all cultures, children are expected to respect their elders. Filial piety is encouraged by many religions as well. For example, the Christian and Jewish faiths are familiar with the Commandment, "Honor thy father and thy mother." Confucianism and Buddhism stress the need to respect your parents, grandparents, and other ancestors. Similarly, Islam and Hinduism emphasize the duty of children to love, respect, and support their parents.

How does filial piety affect death and dying?

- There may be an expectation that the family will care for its sick and dying members. This is commendable, and many families have the skills and resources to do this well. Some families, however, may try to "do it all" and not ask for help when they need it.
- A dying person may try to "hang on" until all the children return home.
- The first-born, and in particular the first-born son, may bear certain responsibilities for decision-making and leadership. Other family members may have prescribed roles as well.

- Children may want to protect a parent from "bad news." For example, children might not want a parent to know that he/she has cancer. Knowing this news might cause the parent to become depressed or give up hope. Even if the parent suspects or knows the diagnosis, he/she may pretend not to know it, and the subject is not discussed. In a Western system that stresses individual autonomy, this may create conflict among family members and with hospital staff.
- Wanting to protect a parent from "bad news" also might postpone a referral to hospice. If the dying person and family do not want to admit that death is coming, they cannot take advantage of hospice services.
- Requests for organ donation and autopsy may be refused. Organ donation and autopsy, which involve cutting, may seem disrespectful of one's parents and ancestors.

Collective vs. Individualistic Decision Making

Cultures differ in how decisions are made. In collective cultures, decisions are made for the good of the group. In individualistic cultures, individuals are encouraged to make decisions independently. When thinking about this concept, remember that there are no absolutes; cultures and individuals may exhibit both collective and individualistic tendencies. In general, though:

- Individuals from collective cultures usually ask their family members to hear information and help make decisions. In some cases, an elder may defer decision making to the spouse, to the eldest son, to another child, or to the person in the family deemed most capable of serving in this role.
- Individuals who are brought up to make decisions independently usually want to hear information about their diagnosis directly from the physician. They may want to make decisions by themselves, and then tell others what they intend to do. They may decide which family members should know of a decision and which shouldn't. Many people from individualistic cultures, however, consult family members and loved ones about end-of-life issues.

Not Wanting to Burden Others Or Ask for Help

Many individuals talk about their reluctance to burden others. This is seen in many cultures for different reasons. Whatever the reason, reluctance to burden others may affect a dying person's willingness to accept help.

- Individuals from individualistic cultures may not want help, even from their children, saying, "I've taken care of myself my whole life. I don't want to be dependent."
- Individuals from collective cultures may see their children's lives as more important than their own. They know their children are busy and don't want to get in the way. Rather than call on their children for more help, they may suffer in silence.
- Some people do not want to burden physicians or nurses unless they have a "big" problem.
- Some people will accept pain and suffering as something they deserve or can learn to live with.
- Some people may not know how to ask for help and need to be encouraged to do so.

Should We Talk About Or Plan for Death?

Some cultures are not sure if it's a good idea to talk about or plan for death. This might translate into a reluctance to complete advance directives or use hospice services.

- Some individuals believe that completing an advance directive is unnecessary or would show a lack of faith in God's plan.
- People who believe in individual karma may feel that advance directives are unnecessary or represent an attempt to circumvent karma.
- Some individuals are more fatalistic than others. They may feel that completing an advance directive would tempt fate and cause death to happen.
- Concerns about tempting fate also might cause someone to postpone use of hospice. If the dying person and family do not want to admit that death is coming, they cannot take advantage of hospice services.

Discernment is a process of letting go of what we are not.

–Father Thomas Keating

Experience With and Respect for Health Care

Different cultures have different experiences with health care and different levels of respect for hierarchy and authority. This may cause some to "do whatever the doctor says" and may cause others to question the doctor and seek other opinions.

- In many cultures, the physician is put on a pedestal, and individuals may defer to him/her in all decisions. Instead of describing their needs or misgivings, they may ask the doctor to decide, saying, "the doctor knows best." If the doctor doesn't have all the information about the dying person's wishes or the family's abilities to provide care or afford medicines, however, he/she might not know best.
- Some individuals, regardless of culture, may postpone seeking help. They might have so much respect for their physician and nurse that they are reluctant to "bother" them.
- New immigrants may come from communities that don't have advanced life-support capabilities. They might not know what CPR is or what a ventilator is. They may insist that the doctor "do everything" without realizing that hospitals can keep people alive forever, even in a vegetative state.
- People who have limited income, have experienced discrimination in health care, or live in communities with few services may be reluctant to plan for death. They may fear that completing advance directives or accepting hospice services might justify the withholding of needed treatments.

Being Buried Whole

Some cultures believe that it is good to be buried whole. These beliefs may lead individuals to refuse organ donation and autopsy.

- In cultures whose traditions involve belief in reincarnation, individuals may refuse to donate organs for fear of being reincarnated without them.
- Individuals from traditions that believe in an afterlife may feel the same way. They would not want to go to the next life without their eyes or liver.
- Many religions discourage the cutting or disfigurement of the body, even after death, discouraging autopsies.

OTHER CONCERNS

Culture and Religion are Difficult to Separate

You may observe situations where there is a blending of seemingly incompatible religious and cultural views regarding death. For example, Buddhists believe that it is not right to cause death. However, Japanese Buddhists who've seen their elderly loved ones die with "too many tubes" acknowledged 2 Japanese concepts that would support the withholding or withdrawing of futile treatment. These are *shikata ga nai,* which means "nothing can be done" or "it cannot be helped," and *akirameru,* which means "to leave things as they are" or "to let things proceed naturally." Here the interplay of religion and culture is seen.

Communication Styles

Different cultures have different rules about communication and different communication styles. In some cultures, it is acceptable to lament and complain out loud to others. In other cultures, news about illness, death, and family troubles is kept inside the family. Some cultures encourage directness, and individuals tell you what they want. In other cultures, people may ask for help in a roundabout way.

True love is not
a feeling by which we
are overwhelmed.
It is a committed,
thoughtful decision.

–M. Scott Peck

ACTIVITY: Case Examples

1. Mr. Jacobs is 86 years old and clearly dying of cancer. His granddaughter, a first-year medical student, has learned about hospice care at school. She asks her mother whether hospice care might be good for her grandfather. Her mother tells her not to talk like that. "Grandpa doesn't know he has cancer and besides, he might live a long time more."

- *How would you interpret this behavior?*
- *What would you do or say?*

2. Mrs. Martinez, an elderly neighbor, had a stroke and was hospitalized. She can still communicate and seems able to make decisions, but refuses to talk to the doctor without her entire family present. The doctor happens to be a relative of yours and has asked you for advice on how to proceed.

- *How would you interpret this behavior?*
- *What advice would you give your relative?*

3. Mr. Smith is dying. His children do not live close by, and Mr. Smith has not told them of his condition. "I've taken care of myself my whole life, and I don't want to be dependent on my kids. Besides, it's none of their business!"

- *How would you interpret this behavior?*
- *What would you do or say?*

4. Mrs. Chung, an immigrant from Korea, is 80 years old and has emphysema and metastatic cancer. Her emphysema is so bad that she cannot move without great distress. Her doctor has recommended hospice care, but the family is against it. "You should be doing everything to save her."

- *How would you interpret this behavior?*
- *What would you do or say?*

REFLECTIONS

Reflect upon what you believe about dying and death.

- *What, if any, superstitions or fears do you have about death?*
- *What were you told about death as a child?*
- *Think of a time when someone you know died.*
  - *Which communication style was used to discuss it?*
  - *What was the dying person told about his/her condition? What were the children told about it?*
  - *What was the dying person's and family's attitude toward asking for help?*

 Write your reflections here.

Love is what you've been through with somebody.

– James Thurber

THE PRACTICE OF MINDFUL PRESENCE

For things to reveal themselves to us, we need to be ready to abandon our views about them.

– Thich Nhat Hanh

What Is Mindful Presence?

Mindful presence is a way of being. It is cultivated through awareness and deep personal introspection. In the flux and flow of dying, where rapid change and unpredictability are common, mindful presence is essential. It may or may not result in action. As we learn to empty ourselves of what we believe, we come to experience what we are. Mindfulness, when practiced regularly and applied to daily life, results in a sense of inner peace while maintaining a focused awareness on the present moment.

One who is mindfully present for another refrains from judgment, demonstrates love, and embodies compassion, often through silence, touch, and gentle words of encouragement and affirmation. Your compassionate and caring presence for another is many things.

- It is one of the most valuable gifts that can be offered.
- It allows the dying person to attend to what is most important and valuable to him/her.
- It allows the dying person to die on his/her own terms, accepted and loved.

Mindful Presence Means Attending the Mystery

We live until the moment of death. Death is part of life; it is the end of life. We do not abandon a mother giving birth, nor should we abandon the dying. Both birth and death are profound mysteries. When a child is being born, we wait with silent anticipation, awe, and uncertainty of what is coming. We offer a few words of encouragement, comfort care, and skilled hands to ease the transition. The mother labors, and the child is born. Dying is no different. It is also a transition that can be eased by your mindful presence. Birth is the beginning of human life, death the ending. As attendants of both, we must do what we can to ease the transition and stand in respect for what is occurring within and outside of all of us.

Mindful Presence Involves "Doing Nothing"

Much of our training and experience has been directed toward doing for others and offering tangible support and care to those in need. Because we live in a death-denying culture, dying may feel frightening and unfamiliar to us. In our hesitance to embrace death, our uneasiness may lead to a desire to intercede and "do something" as a way to show our care and concern. But as people approach death, there is often little we can do for them. We cannot make them better, we cannot save them from this experience, and we cannot accompany them on their journey. As such, we may feel frustrated and ill-equipped to provide compassionate care.

Learning the difference between "being" and "doing" is a necessary skill for those who work with the dying. Although your service is a valuable gift to the dying and their loved ones, it may take a conscious effort to feel comfortable "doing nothing" and just practicing mindful presence. Remember that being mindful does not mean being detached from others or being cold and uncaring. Rather, it involves an alert and focused participation in living, often without action.

While you may utilize a number of learned skills working with the dying, the foundation of this ministry is mindful presence. As death approaches, there will be fewer tasks to perform, and words will have less meaning. Your loving presence will become a lighthouse of strength, for you are holding a sacred space in which the dying can attend to their transition. As we learn to surrender our preconceived ideas about how things should be, we become more comfortable with the way things are. You cannot die for another, but you can support his/her transition through your loving intention to be present. Because many dying people fear abandonment, your mindful presence is the greatest gift of all.

Learning how to "be" instead of "do" requires a willingness to enter into one's own fears about loss of control and uncertainty; to be empty of opinion, preconception and judgment; and to take in cues from the environment and respond when appropriate.

Hold fear in one hand. Hold love in the other. Holding both, choose love and choose love again.

–Pat Rodegast

Clearing Barriers to Mindful Presence

There are many barriers to being mindfully present. These include unfinished business, family conflict, fear, guilt, denial, , and grief. As many of these issues surface during the dying process, close family members may not always be the best ones to provide spiritual care. For example, there may be unfinished business for a family member with little time and opportunity for resolution. In these cases, it is difficult for family members to just "be present" with their loved one.

As one who cares for the dying, you may need to be aware of the barriers to spiritual care that exist within yourself. If you feel guilty about a death of a loved one in your past, acknowledge it. But don't bring your guilt into this situation. You also may identify barriers for the dying person's loved ones and, if asked, you can link them to clergy and other resources that can provide assistance.

ACTIVITY: Sacred Centering

There are many methods to becoming more mindfully present. One method is the Centering Prayer. Although there is no "list" of qualities or results that occur from this practice, people report feeling more open, loving, receptive, and compassionate and less judgmental, biased, and reactive.

Centering or contemplative prayer comes from the early Christian tradition. It focuses on the divine presence within, rather than outside of us. Many traditions have similar meditations and exercises.

The purpose of this practice is to move beyond words, thoughts, and emotions, so we can enter into a silence where a deeper communion with the higher power or divine nature is experienced. The following activity is one you may practice daily.

Sacred Centering

Choose a word or phrase that feels sacred to you. This word will become the single symbol of your intention to surrender. Through focus upon this word alone, you become more deeply connected and aware.

1. Find a place away from noise where you will not be distracted. Sit comfortably with your eyes closed. Breathe slowly and deeply as you enter into the silence. With each full breath, you are relaxing and going deeper within. If you become so relaxed you fall asleep, return to the practice when you reawaken.
2. Think only of your sacred word or phrase. As thoughts arise in your mind, do not be upset. Just notice their entry, return to your sacred word, and breathe gently.
3. Begin with a period of 10 minutes. After you are more comfortable with the practice, it can be extended to 20 minutes or more.
4. At the end of your practice time, dwell in the silence for a few minutes.

You may initially notice disturbances such as uneasiness, restlessness, itching, twitching, or other minor discomforts. Just notice them and return to the practice. After a while you will find it easier to go more deeply into the practice without distraction.

Sacred Centering for Others

You may also use this meditation for the dying person or their loved ones. To set the intention for another, use a word that most closely represents the expressed or observed need of the person. For example, if peace is intended for the dying person who is experiencing fear, you may place the person at the heart of your practice and focus on the word "peace."

The best and most
beautiful things in the world
cannot be seen or touched...
but are felt in the heart.

– Helen Keller

REFLECTIONS

- *How have you been a presence to the dying?*
- *Does "doing nothing" make you feel uncomfortable or inadequate? Why?*
- *How do you become aware of other's spiritual needs?*
- *Have you ever said or done something to someone who was dying that you wish you hadn't?*
- *How would Sacred Centering have helped?*


Write your reflections here.

SAYING GOOD-BYE

Persons who are dying often want "permission to die" from those they love. Often they want to be assured of 5 things:

- Things they were once responsible for will be taken care of.
- The survivors will survive without them.
- All is forgiven.
- Their life had meaning.
- They will be remembered.

Saying good-bye is not easy. Yet, it may be important for the dying person and his/her loved ones to do so. Take advantage of opportunities when the person is lucid and communicative to facilitate the "saying good-bye" process.

If the dying person is not lucid, or is in a coma, remember that hearing is the last sense to leave. Assume everything you say can be heard and understood, even if the person is not responsive. Never speak about the dying person as if he/she was not in the room.

Some people feel comfortable lying in bed next to their loved one as they say their parting words. Others may want to simply hold their loved one's hand. If music, chanting, or prayer is used to assist the dying, let it be comforting and familiar, making way for gentle passage. The dying person's body language will let you know if these sounds are welcome and soothing.

Dr. Ira Byock, noted expert in end-of-life care, says there are 5 important things a dying person needs to say at the end of life:

"I forgive you." "Please forgive me."

"I love you." "Thank you." "Good-bye."

It may be difficult, however, for the dying person to do this. Consider beginning yourself. You may want to ask the dying person to forgive you for any hurt you may have caused. Thank that person for his/her contributions to your life. Express your love. Say good-bye. It is alright to tell the person he/she will be missed. This will help to give the dying permission to do the same, if needed.

Awareness of death is the very bedrock of the path. Until you have developed this awareness, all other practices are obstructed.

–The Dalai Lama

Being Present At the Moment of Death

Even with all the preparation and knowledge that death is coming, the moment of death is not easy to see. Even those people who are closest to the dying person may choose to be absent.

The decision to be present at the moment of death depends on many things. Do not judge others if they choose not to be present at the moment of death. It is not uncommon for the dying person to wait to die until loved ones have left the room. Make sure you allow for this. Sometimes, if a person seems to be holding on, you may simply say, "I'm going to leave the room for awhile. I love you."

In some cultures, specific prayers or sutras may ease the passage to death. These may be comforting both to the dying person and to his/her family.

The Universal Protocol

Whatever you say, let your final words be those of loving kindness. You are "gifting" these words to the dying person as well as to yourself. Adopt a "universal protocol" when caring for all people, regardless of gender, beliefs, values, or ethnicity.

- Be non-judgmental.
- Treat each and every person with dignity and respect.
- Be authentic.
- Listen from the heart.
- Don't take over…focus on watching and learning.

Above all, remember that you are a caring presence. Your presence for the dying person and his/her loved ones indicates loving kindness, support, and compassion. These qualities transcend culture.

An Opportunity for Your Own Spiritual Growth

Use this time to enrich your own spiritual path, whether you are a primary caregiver, visitation minister, community volunteer, or friend. Do not impose your culture or faith on another. Instead, know in your heart that caring for the dying is noble work.

ACTIVITY: Choices in Dying

Read and discuss the following 2 stories:

1. A Mother's Death

No one likes to think about the death of a parent, much less experience it. On March 7th, I received a call from my mother. She had fallen, and although no bones were broken, I am sure it must have weakened her. She had pulmonary problems for years, probably starting after the death of our father; a low-grade infection was always there, but never too obvious. She was taking some antibiotics, and the doctors had decided that she needed to take more. As always, she took charge and decided that this was not what she wanted to do. Her phone call was explicit: "Please come home now, as I would like to die within the next week."

Having taken care of our father for almost 2 years he suffered with colon cancer, she fully knew that death usually does not come quickly or easily. She had administered his morphine for at least a full year before he died, even giving him his last shot before his death. She wanted to be in control of her own death and decided that she would take no medicines of any kind and no food or water. Whether she had thought this out before hand, I do not know, but she was adamant that this was the course she would take.

The family descended like angels; it was their turn to be there for her. They just took over and helped in every way possible. They spent time alone with her, remembering the past they had all shared together. Two grandchildren played cards under her bed, with her listening and enjoying it all. She was never alone, always surrounded by family. It was so hard not to offer a drink, and she finally let us wet her lips and tongue, more for our sake than hers, I think. No food, of course, and as she constantly and firmly insisted, no pain medicine. We will never know if there was pain, as we had to take her word.

She drifted in and out of consciousness, always alert when awake, answering any questions about how she felt and if we could do anything for her. She gave off such strength and confidence in what she was doing, that there really was no room for doubt or

fear. Our task was to be there to support her, in her way. I was losing my best friend and mother who had been by me all my life, and I could see a long time ahead without her. We reminisced about a lot of things, and when late at night she would awake, we would think about the past and start laughing.

And so it went. A week to say good-bye with enough memories shared to last our lifetimes. She gave and gave in life, and in dying, gave even more. She gave us the life experience of dying with dignity, to be in charge of our own deaths and to do it in the way we felt was right. I am not afraid of dying after seeing the deaths of both parents, who died at home in their own beds, with their family surrounding them. Dying is such an important part of living, something that faces all of us. I hope that when it is my turn to die that I will be able to choose the way, with my family in complete agreement.

Seeing into darkness is clarity... This is called practicing eternity.

– Lao-Tsu

2. Light From a Dark Place

Mira was a young woman with a remarkable spirit; her life bore witness to that. She seemed to always put herself on the front-line, rallying for those less fortunate than she. Her personal life had not been easy, but she always had a smile and a warm heart for everyone, the kind that could light up a dark place.

Upon a routine mammogram, a lump was discovered in her right breast. The biopsy revealed it was malignant. Mira chose to have both breasts removed. That was when I first met her. The surgery did not remove all of the cancer, and it was aggressive. Although Mira believed in alternative medicine, she chose the most aggressive form of conventional treatment—a new and powerful chemotherapy with many unfavorable side effects. She knew her chances for survival were slim, but took a chance in the possible hope for a cure.

Each time I came to visit, her physical body grew weaker and frailer. She had asked me not to pray for her, but rather to sit near to her, hold her hand, and just be her friend. There were painful side effects from the treatment, yet her spirit was radiant. In the months ahead, Mira was in and out of the intensive care unit, through peaks of hope and valleys of despair. When she was

feeling well enough to go home, she would, and then return to the hospital when the next crisis occurred.

The aggressive treatment she had chosen to arrest the cancer finally caused her kidneys to fail, and she was placed on dialysis. Dialysis took a further toll upon her body and her emotions. When asked if she had regrets for choosing conventional treatment, she had none; she had made the choice she felt was best at the time. In the final stages of living, when language no longer became a way to connect us, we carried on our conversations with glances of knowing and deep appreciation for each other.

Mira was rushed to the hospital on the last day of her life when her heart stopped. Although attempts were made to resuscitate her, nothing more could be done. She "fought" for life until her last breath. Mira was a great teacher to me, for through her bravely living her dying in each moment, she taught me what it meant to be truly alive and how to know light from the darkest of places.

Discussion

These 2 cases illustrate the vast differences in end-of-life choices. In the first, a woman who is 95 years old and has led a full life chooses no intervention to prolong her life. In the second illustration, Mira, a young woman of 45, opts for the most aggressive form of treatment in the small hope that her cancer might be cured. As you can see, people make different choices, depending on who and where they are in life. There are no right or wrong choices, only personal choices that reflect the values and beliefs of each person.

- *Discuss feelings and reactions from these stories.*
- *Share a story from among the group.*

REFLECTIONS

Answer these questions for yourself.

- *What does your culture teach about choice in dying?*
- *What are some of the rituals and customs that your culture uses to "say good-bye" to those who are dying?*
- *Are there any beliefs or superstitions you have about where a person should die?*

 Write your reflections here.

Care of the Bereaved

THE JOURNEY OF GRIEF

The Individuality of Grief

In this module, you will learn about a general "roadmap" that experts have developed to describe the grieving process, or the journey of grief. You will learn what experts feel is "normal" grieving and what is "abnormal" or "complicated" grieving. As you learn what is considered "normal," you will feel more comfortable with the bereaved as they express their grief.

Keep in mind, however, that each person's grief is unique and someone may, or may not, follow the "roadmap." Experiences and expressions of grief are as individual as fingerprints. Gender, culture, personality, earlier losses, beliefs, values, and religion are among the many factors that influence the way in which we grieve. There is no "right" way to grieve and no specified length of time required for the grieving process.

There is no "recovery" from grief, for grief is not an illness.

In fact, most people never "get over" their loss completely. Rather, they can come to grips with the loss and move on. Experts agree that individuals "emerge" from their grieving when they reach a state of acceptance and feel a re-emergence of hope, however long it takes. As companions to the bereaved on their personal journey of grief, you can help to assist in this process.

Grief, Grieving, Mourning, and Bereavement

Grief, grieving, mourning, and bereavement are terms that are often used interchangeably, but there are some distinct differences.

Grief

Grief is defined as the deep and poignant distress caused by the loss of a loved one.

- Grief is intimate, personal, and intense.
- Grief affects us physically, emotionally, socially, mentally, and spiritually.

Grieving

Grieving is defined as the process of feeling and experiencing grief, of coming to an acceptance of the death, and to seeing the reemergence of hope.

- Grieving is an internal process (or journey) that takes a long time to complete.
- Like any process, grief may be experienced and expressed differently at different points throughout the journey of grieving.
- Grieving carries the potential for transformation. As one proceeds through the grieving process, beliefs, values, and perceptions of life may change.

Mourning

Mourning is both the outward expression of an inner state of grief (similar to grieving) and the display of the customary signs of grief for a death (such as rituals surrounding a death). Because people in all cultures die, all cultures have rituals and guidelines for acceptable ways to mourn. In Western culture, the most familiar mourning ritual is the funeral or memorial service. Wearing black for an extended period of time or wearing a visible symbol, such as a ribbon or armband, alerts others that an individual is mourning. Mourning allows an opportunity to give voice to one's inner feelings of pain, anguish, despair, sadness, and anger, and to release them. The words "grieving" and "mourning" often are used interchangeably to refer to the expressions of grief.

Bereavement

Bereavement, or the state of being bereaved, is the encompassing experience brought about by the loss of a loved one by death. Nothing is spared. The past, present and future are all impacted by the loss.

Common Expressions of Grief

Grief is expressed in different ways. Some people want to "talk out" their grief. Others may keep to themselves for a period of time. Some people may be very emotional or cry a lot. Others may not shed any tears. Returning to daily routines as soon a possible may be comforting to certain people. Others may withdraw and become introspective.

Regardless of expression, remember that grieving is about change and movement. Standing still in the face of change takes a tremendous amount of resistance and can lead to illness or stagnation. Thus, helping others to find safe and acceptable ways to express their grief and move through their grieving process is a very important part of your ministry.

Each person's journey of grieving is unique. But there are some common emotional expressions of grief. These include:

- **Sadness.** Feelings of sadness may seem overwhelming. Waves of sadness are extremely common and sometimes can seem unbearable. Survivors may feel they will never be happy again. Over time, the intensity of sadness lessens. Remember, however, that most people never "get over" their loss completely.

- **Loneliness.** The loss of a loved one causes feelings of loneliness. For most, returning to an empty house and revisiting places that the survivor and the deceased once frequented will trigger these feelings. Evenings and weekends may be the most difficult, as there is less activity and more quiet time to think about the deceased and to feel lonely.

- **Anger.** The bereaved may feel anger toward the deceased, the doctors, family members, or friends. They may even be angry with God. Anger may be turned inward and result in depression, withdrawal from activities and work, or physical illness.

The foundations of a person are not in matter but in spirit.

–Ralph Waldo Emerson

- **Guilt and blame.** Bereaved persons may go through a series of "if onlys." Thoughts of "I should have done more" or "If only I had…" are common. Blame may be directed at others or at oneself. These thoughts are normal. But if they continue to be prominent, they may result in a lack of self-forgiveness and may complicate grief.

- **Anxiety.** The death of a loved one often involves the death of plans for the future together. The survivor may feel completely lost and ungrounded. These feelings are often accompanied by intense anxiety over what the future may hold.

- **Relief.** If the death has followed a long illness, there may be relief it is finally over. This is normal. Survivors may feel guilty, however, if they feel relieved and may be reluctant to acknowledge that feeling or share it with others.

- **Thankfulness.** Some people may feel that the death was "a blessing." This does not mean there will not be sadness and readjustment. People need to be given permission to feel OK about a death. A death can be celebrated as individuals express thanks for knowing the person who died and for the time spent together. Gratitude and thankfulness are great healers.

- **Emotional ups and downs.** The initial reaction to a death may be shock and denial, followed by intense grieving accompanied by pain, "working through grief," and readjusting. Thus, it is common to have mood swings after a loved one's death. One day a person may feel as if he/she is returning to normal and the next day may be "down in the dumps" again. Anniversaries of the death, birthdays, holidays, seeing someone who looks like the person, or visiting a familiar place may trigger an "emotional down."

Love is an act of endless forgiveness, a tender look which becomes a habit.

– Peter Ustinov

There are several physical responses too. These include:

- **Insomnia and bad dreams.** Sleep is essential for the well-being of the bereaved person. However, insomnia and bad dreams are common, particularly in the first stages of grieving. Vivid dreams involving death or about the deceased are frequently reported and may be upsetting. These are a normal part of adjustment.

  Tip: Relaxation techniques, meditation, music, or mild sedatives could be used to help the survivor sleep better. Having an opportunity to talk about the dreams can help the bereaved to move through the grieving process.

- **Physical complaints and loss of appetite.** Physical complaints are common, such as stomachache and tightness in the chest and throat. A bereaved person may comment that his/her stomach feels like "it is tied in knots." Survivors may complain of a loss of appetite.

  Tip: Eating several small meals and snacks may be easier than eating large meals. In the initial stage of grief, the provision of nutritious meals and snacks can help, as survivors may not be motivated to prepare meals for themselves.

- **Confusion.** Confusion, memory loss, and inability to concentrate are often seen in the early stages of grief. Survivors often complain of feeling that they are "going crazy." Lack of concentration and inability to do routine tasks contribute to this feeling. The initial intense emotions of grief temporarily affect the way the mind and body function. These are normally temporary conditions. If they persist, this may signal depression and a need for professional help.

  Tip: It is helpful to acknowledge this response to grief and to let the bereaved know that this response is common. Offering to listen, to provide reminder calls, to escort the person to appointments, and so forth, may keep the bereaved from becoming isolated at this time.

MISPERCEPTIONS ABOUT GRIEF

There are a number of commonly held misperceptions about grief, which can present significant barriers to aiding someone who is bereaved. The statements below are not helpful!

"You should be over this by now."

WRONG! Grieving people need a lot of support over a long time. Some cultures have a set period of mourning, after which the person is expected to get on with life. Although these periods of mourning can help facilitate healthy mourning, they may overlook the fact that everyone's grief is unique and is influenced by many factors. It is generally true that the passage of time tempers the extreme feelings of sadness, but the feelings may never disappear entirely. Experts now believe that one does not "get over" the loss, but rather adapts and integrates the loss into their lives.

"Time heals all wounds."

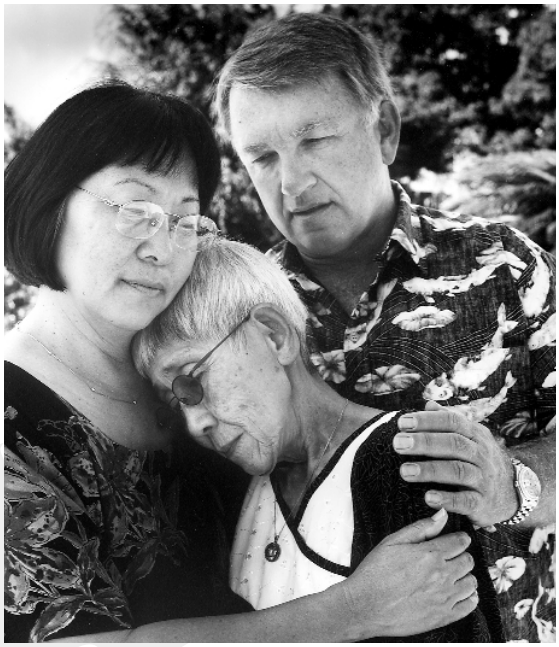
WRONG! Time and eventfulness may never fill up the emptiness caused by the loss of someone close to us, but it can temper the harsher feelings that come in the first year of grief.

"If you're not crying, you're not really grieving."

WRONG! Although western culture has become much more supportive of public displays of emotion, there are people who do not cry after the death of someone they love. Although the majority of these appear to be men, some women do not express their emotions through crying either. Additionally, older people may be more reserved about public expressions of emotion. To an observer, it may seem as if they are "blocking" their feelings. In the journey of healing through grief, crying does not necessarily mean that a person is getting better. Although crying readily expresses emotion and releases energy, crying in and of itself does not help to complete the tasks necessary to reinvest in life. Some people can, and do, express a great depth of emotion and never cry.

"Men are not very good at grieving" and "Real men shouldn't cry."

WRONG! There is often a gender bias with regards to experiencing grief and expressing emotions. These stereotypes often affect the way men and women feel about dealing with a loss. Oftentimes, men feel restricted from sharing because of social, gender, or cultural expectations. Women often are seen as more ready to accept help and express emotion, 2 things that are critical in the process of grieving. Since men are perceived as less willing to accept help and express their emotions in a time of loss, they are seen as having more difficulties in dealing with their grief. However, this generalization is not always true and this stereotype is not helpful.



The goal is to live in the midst of grief, not to merely survive. Remember... and embrace life once again.

ACTIVITY: Becoming Sensitized To Losses Surrounding Death

What you will need:

- 5 squares of different colored paper or index cards for each participant
- Pens or pencils

Instructions

Write specific examples of the things in each of these 5 categories that are most important to you.

- Yellow card – List the jobs or other roles you perform that are most important to you (e.g., spouse, parent, teacher, volunteer)
- Orange card – List your favorite hobbies and leisure activities (e.g., crafts, puzzles, travel, sports)
- Green card – List your top-most important relationships (e.g., with specific family members, friends, and so forth)
- Pink card – List your favorite material possessions (e.g., house, car, boat, photos, jewelry)
- Blue card – List the values that you hold most dear (e.g., honesty, forgiveness, spirituality, helpfulness, loyalty, responsibility, kindness, resourcefulness)

Arrange the cards in order of importance, with what is most precious to you placed on bottom of the stack. Close your eyes while the facilitator or another member reads the following guided imagery exercise.

You have just visited your doctor, who found a small lump that is suspected to be cancerous. You are frightened and expect the worst. A biopsy cannot be scheduled for 2 days. You check into the hospital for a biopsy of the lump to determine whether or not it is cancerous. Another 24 hours goes by. The report comes back positive. You have cancer (give up your first card).

The outlook is not good as this cancer spreads rapidly. You hope they caught it early. Surgery is scheduled the following week–more waiting, more anxiety. They remove the entire tumor. But they fear it has spread to the lymph nodes, and other vital organs may be affected. The prognosis is poor (give up your next card).

Your doctor has also ordered radiation and chemotherapy as adjunct treatments, hoping for a cure. These treatments make you feel worse. Your energy is depleted, you are depressed, you have lost 20 pounds, and all of your hair has fallen out (give up your next card).

You feel of no use to anyone, and you are angry that this has happened to you. After 6 months of intensive treatment, you realize you are not going to get better. You are going to die (give up your next card).

Discuss the following questions.

1. What color is the remaining card? What did you write on this card? How are the category and the items you wrote important to you?
2. How did it make you feel to lose the cards one by one? Which ones were hardest to let go? How can the last card sustain you through the loss of the previous cards?
3. What did you learn from this exercise?

REFLECTIONS

- *What are the common ways in which you express grief, or think you might express grief?*
- *If you were grieving, to whom would you feel most comfortable expressing your feelings?*
- *What would you want people to say to you if you were bereaved and experiencing these feelings:*
  - *Sadness*
  - *Guilt*
  - *Thankfulness*
  - *Confusion*

 Write your reflections here.

THE PATH AHEAD

In the previous session, we learned that grief is a journey and that every person's grief is unique. We examined some of the common expressions of grief, both emotional and physical. In this session, we will look more closely at the "roadmaps" that experts have developed to describe the journey of grief.

Although "roadmaps" may be helpful, remember that each person will find his/her own way to wholeness and integration. Thus, there are infinite pathways for individuals to work through their grief. As spiritual caregivers, we must not be enslaved by the "roadmaps." Instead, they should be used as a foundation from which we build and create an environment that can embrace the uniqueness of each individual and facilitate healing and transformation.

If one is to die peacefully, one must begin helping oneself long before one's time to die has come.

–Swami Muktanada

The Tasks of Mourning

William Worden, noted expert on grief, suggests there are four "tasks" of mourning that survivors of loss must accomplish to heal and get on with life. These four tasks include:

Task 1. Accepting the Reality of the Loss

When someone we love dies, even when death is expected, there is a feeling of unreality—that the death did not really happen. The first task of grieving, then, is to accept death as real and to acknowledge the loss as permanent. Our loved one will not be coming back. Disbelief, denial, and bargaining are common during this time. To speak about the loss can affirm it and make it "real" at an intellectual, emotional, and spiritual level.

How you can assist:

- Listen and be present for the survivor. Listening as the survivor talks about the loss helps the survivor accept the reality of the loss.
- Compassionately attend to the grieving person as the stories and memories of the deceased are told. Remain patient if the same stories are told many, many times. These have significant meaning for the survivors.
- Offer practical help, especially with tasks that the deceased used to perform.

Task 2. Working Through the Pain of Grief

Grieving is hard work; it is also painful. If grieving is suppressed or delayed, it can potentially prolong the mourning process. Society in general, and some cultures in particular, may be uncomfortable with expressed feelings. It is important for the individual to acknowledge his/her pain and release it. Feelings need to surface and be expressed.

How you can assist:

- Allow adequate time and a secure place for the survivor to express his/her feelings openly. Find a peaceful and safe place away from interruptions and distractions.
- Do not distract the mourner from this task. The feelings generated by grief -- anger, isolation, and deep sadness -- are painful, but cannot be denied. Do not attempt to provide "comfort" during this time by distracting the survivor from expressing feelings. This takes the focus away from the necessary task of mourning.
- Demonstrate genuineness, empathy, warmth, compassion, and sensitivity. This is the place to show unconditional love.
- Discourage the survivor in making major decisions at this time. Perceptions and judgment will change as healing continues.
- Offer practical help, especially with tasks that the deceased used to perform.

Task 3. Adjusting to an Environment Without the Deceased

Usually about 3 months after the death, the realization of living without the loved one becomes more real. The survivor may have to adjust to new roles and responsibilities, such as living alone, raising children alone, and managing finances alone. The survivor often is not aware of all the roles played by the deceased until the death occurs. This can be a stressful and difficult time of adjustment, and the survivor may feel helpless and become dependent on others. A change in one's identity and philosophies can be challenging.

How you can assist:

- Remind the survivor that this is not the time to make major decisions. Perceptions and judgment will change as healing continues.
- Offer emotional support.
- Offer practical help.

Task 4. Beginning a New Life – Emotionally "Relocating" the Deceased and Re-investing in New Relationships

This fourth task requires that the mourner withdraw emotionally from the deceased person and reinvest the energy into new relationships. This is a difficult task. Many people get stuck here only to later find out that life seemed to stop at the point the loss occurred. It may feel as if withdrawing energy from mourning dishonors or dismisses the importance of the loved one. However, this task does not require that the deceased be replaced or forgotten. Instead, the loss is integrated into the weave of the survivor's life, and the loss no longer dominates one's thoughts. This task is accomplished when the survivor learns to live again with the memories associated with the deceased without experiencing pain.

It is very deep to have a cup of tea.

–Katagiri Roshi

How you can assist:

- In time, gently encourage the survivor to form new relationships and reconstruct meaning for their lives. Do this with actions, not words. Invite him/her to social gatherings and to other events where new relationships can be formed.
- Acknowledge that the loved one can never be replaced. Suggest, however, that by investing in new relationships, life may again have meaning.
- On the other hand, be alert to survivors who rush into new relationships because they fear being alone. They may not have allowed themselves time to grieve the loss.

Kenneth Doka, a minister and grief counselor, adds a fifth task:

Task 5. Reconstructing Belief Systems Challenged By the Loss

After a loss, the foundations of one's faith may be shaken and one's beliefs may be challenged. What once was comforting and had meaning may now seem empty. Reconstructing meaning and purpose within the context of faith is an important task.

How you can assist:

- Be aware that spiritual distress can be a part of grieving. Listen without judgement.
- Avoid the tendency to quote from the teachings of the faith tradition as your main means of providing comfort.
- Support the survivor as he/she reconstructs his/her belief system. Again the key is to listen without judgement.

Be gentle and kind in the face of grief.

Be patient and understanding.

Remember, grief is ongoing.

Every person is unique.

A TIMETABLE FOR GRIEF?

One of the most frequently asked questions is: "How long will these feelings last?" This timetable describes a general process through the first 2 years of grieving. Remember, however, that individuals will vary and that grief truly has no "time limit."

Month 1

In the first month, grieving persons may be so busy with funeral arrangements, visitors, paperwork, and other immediate tasks that they have little time to begin the grieving process. They may also be numb and feel that the loss is unreal. The shock can last beyond the first month if the death was sudden, violent, or particularly untimely.

Month 3

The 3-month point is a particularly challenging time for many grieving persons. Visitors have gone home, cards and calls have generally stopped coming in, and most of the numbness has worn off. Well-meaning family members and friends who do not understand the grieving process may pressure the grieving person to "get back to normal." The grieving person is just beginning the very painful task of understanding what this loss really means.

Months 4 through 12

The grieving person continues to work through the many tasks of learning to live with the loss. There begins to be more good days than bad days. Difficult periods with intense emotion will arise, sometimes with no obvious trigger, even into the last half of the first year. It is important that the grieving person understands that these difficult periods are normal, rather than a setback. The 6-month mark may also be an especially difficult time.

First Anniversary of the Death

Reactions to the 1-year anniversary of the death may begin days or weeks before the actual date. Many people describe reliving those last difficult days. Even individuals who have been doing very well toward the end of the first year may be surprised at how intensely the 1-year anniversary affects them. People generally welcome additional acknowledgement or support during anniversaries.

The Second Year

Most grieving people agree that it takes at least 2 years to start feeling like they have established workable new routines and a new identity without the deceased person. Many of the tasks of the second year have to do with re-assessing goals, discovering a new identity, and creating a meaningful life style.

Significant Anniversaries

During the first 2 years, personal and public holidays present additional challenges. Birthdays of the deceased and other family members, family and school reunions, wedding anniversaries, and anniversaries of the death, can all be difficult periods. Medical anniversaries, such as the date of the diagnosis or the date someone was hospitalized or came home from the hospital, can also bring back memories.

How you can assist:

- Don't be afraid to talk about the deceased person.
- Grieving people have a special need to be acknowledged on holidays, birthdays, anniversaries, and other significant days. These are important opportunities to let survivors know you have not forgotten their grief or the person who has died.
- Some survivors have more difficulty than others with holidays. Holidays tend to make survivors sadder and more depressed than other days. However, those with strong family support may actually enjoy the holidays and we should not assume that every grieving person will have difficulty with holidays.

ACTIVITY: Case Example

Divide into groups of 2 or 3. Choose one or more of the following vignettes for discussion. Each vignette illustrates an individual who has not yet "completed" a task of grieving. Identify the task, see if you can tell where the individual is "stuck," and discuss how you would assist them.

Vignette 1. Mary Ann is a young woman of 23 years. Only last year, she and her husband Michael were married. Michael was killed in an automobile accident six days ago. When you ask how she is, she states, "I can't believe he is really dead. I had the most vivid dream last night where he spoke to me. I could hear him loud and clear. It feels like he's still alive. I just can't believe it."

Vignette 2. Mrs. Palmer is a well-to-do woman in her 60's. Her husband died suddenly of a heart attack 2 months ago. He had always taken care of everything. She never had to balance a checkbook, pay bills, or make major decisions. Since his death, she has been overwhelmed by new roles and responsibilities. Mrs. Palmer appears to be confused, anxious, and depressed. She says, "I'm not sure who I am anymore."

Vignette 3. Matt, a 49-year-old businessman and single father, is a member of your faith community. It has been four months since his only child, an 8-year-old daughter, died from cancer. You have never seen him express any emotion about her death or talk about her. In fact, after the funeral, he immediately returned to his job and now works long hours. When asked how he is doing, he replies that he is fine.

Vignette 4. Mrs. Chang had always been very active in your community, always finding ways to help others. When her husband died 18 months ago, however, she stopped coming to church and participating in group functions. When you visit her and ask how she is doing, she says that her life no longer has meaning. She says that she still sees and feels her husband everywhere and in everything she does. Nothing in the house has changed. Mr. Chang's belongings are exactly where he left them. Mrs. Chang confides that the pain of losing her husband has been so severe that she does not want to experience love or attachment to anyone else.

REFLECTIONS

- *Think about someone close to you who has experienced the death of a loved one. How did they go through the grieving process? How long did it take? Were there times that he/she seemed to get "stuck" and unable to move through the grief?*

- *If you have lost a loved one, how did you go through the grieving process? How long did it take? Were there times that you seemed to get "stuck?"*

 Write your reflections here.

WHEN GRIEF BECOMES COMPLICATED

Complicated Grief

In the process of healthy grieving, most people ultimately reach a state of acceptance, where conflicts related to the loss are resolved. This may take a year or 2, but the grieving person is making observable progress.

Grief becomes "complicated" when survivors are unable to reach resolution and come to an acceptance of the loss. Grief can become complicated when the survivor does not want to talk about his/her feelings and is not letting go of the loved one.

The following is a list of signs and symptoms that MAY signal "complicated" grieving if they are persistent. Remember, however, that many of these symptoms will occur in the early months following a death, but they should lessen over time.

Physical

- Persistent weight loss
- Alcohol or drug abuse
- Depression
- Prolonged sleep disturbances
- Prolonged neglect of personal hygiene and health

Emotional

- Persistent disbelief about the death
- Preoccupation with thoughts about the deceased
- Prolonged feelings of numbness or hopelessness
- Searching and longing
- Behavioral problems (work or home)
- Talk of suicide
- Persistent hostility or anger toward loved ones
- Persistent disinterest in everyone and everything

You cannot prevent the birds of sorrow from flying over your head, but you can prevent them from building nests in your hair.

– Chinese proverb

Functional

- Continued inability to care for oneself
- Continued inability to care for one's family
- Continued inability to function in society

Characteristics of Healthy vs. Complicated Grief

Healthy Grieving	Complicated Grieving
Can experience moments of joy amidst deep sorrow.	Is in a chronic state of despair and hopelessness.
Openly expresses anger.	Anger may be repressed, suppressed, or turned inward.
Receives comfort measures from others.	Resists or refuses help from others.
Physical complaints such as insomnia lessen over time.	Develops persistent physical complaints, existing conditions may worsen.
Feelings of guilt and despair are time-limited and situation-specific, not constant.	Feelings of guilt, low self-worth, self-blame, and despair are chronic and may lead to depression.

Factors That Complicate Grieving

- **Lack of understanding of what grief is.** Individuals who do not understand what grief is may be extremely upset by the range of emotions they are feeling.

- **The cause and circumstance of the death.** Today's deaths are complicated in and of themselves. Deaths due to AIDS, suicide, drug overdose, certain types of diseases, murder, and even some forms of cancer may be socially stigmatized. Traumatic or sudden deaths are particularly difficult as there is no time to anticipate the death. Deaths that are expected may provide opportunity to mourn before the death actually occurs. However, the ability to extend life in terminal illness can delay death and cause complicated mourning, before and after a death has occurred. Perceptions and beliefs about the nature and circumstances of these kinds of deaths may affect one's ability to express grief and get support.

• **The relationship to the deceased.** Depending upon the nature of the relationship to the deceased, grief reactions will differ. Losing a partner or a child means that the former life with that person will cease. If the relationship was good, the survivor may mourn the loss of plans and hopes for the future as well. If the relationship was painful or abusive, the survivor may have conflicting feelings, such as relief and guilt.

• **The "new" world.** The nuclear family of the western world has largely replaced the collective and extended family that once lent support to survivors grieving the loss of a loved one. Many of our families are likely to be separated, with children, siblings, and parents living in different places. The "computer generation" may become more insular and isolated and not seek assistance from others. This lack of support may negatively affect the grieving process. On the other hand, technology affords "instant" communication and can strengthen bonds and connect families as never before.

• **Additional stressors related to bereavement.** These include taking on more roles and responsibilities, changes in life style, and financial worries.

• **Concern for other survivors.** A survivor may be overly concerned about the welfare of others and put his/her grief "on hold."

• **Presence of recent multiple losses.** Grieving is complicated when the survivor is coping with other losses at the same time, such as retirement or relocation.

• **Low self-esteem.** Feelings of worthlessness and guilt may become more pronounced for a bereaved person with low self-esteem, especially if he/she is used to discounting his/her own rights and feelings.

• **Health problems.** Chronic physical and mental illness, especially depression, may be exacerbated by grief and may complicate the grieving process.

What lies behind us and what lies before us are tiny matters compared to what lies within us.

– Ralph Waldo Emerson

• **Uncertainty about the death.** Grieving can be complicated when the death has not been confirmed or a body is not found, such as in the case of soldiers who are missing in action or people who are kidnapped.

High Risk Groups

Groups tending to be more at risk of "complicated" grieving include:

- Young adults who are widowed
- Children who are not supported through grief
- Parents who have lost a child
- People of low socio-economic status
- People who are vulnerable and dependent on others

And we must extinguish the candle, put out the light and relight it; Forever must quench, forever relight the flame.

– T. S. Eliot

When to Seek Help:

Seek help when:

- You see signs and symptoms of "complicated" grieving.
- You are uncomfortable during a visit with the bereaved.
- Your intuition signals something is "not quite right."
- You feel unskilled in handling a particular situation.

An important person to turn to for help would be the bereaved person's physician. Discuss your concerns with the bereaved person and suggest that he/she visit the physician. You may want to help make the appointment and write a list of things that the person should discuss with the physician. You may also want to accompany the person on the visit and help take notes.

Other sources of help include close family members of the bereaved, your pastor, and other people in your bereavement ministry who should have a list of community resources.

Also, it is important to have regular "de-briefing" sessions with members of your church or temple's outreach ministry group to prevent burnout, to help with difficult cases, and to talk through your own issues.

ACTIVITY: Case Example

Divide into groups of 2 or 3. Read each vignette and decide whether the individual is experiencing "normal" or "complicated" grieving. In each case, discuss what you would do.

Vignette 1. Mrs. Lee just lost her husband of 50 years. She appears very confused and has stopped cooking for herself. She has moved in with her eldest son and is completely dependent on his family for emotional support. They are also helping her with the funeral arrangements and financial matters.

Vignette 2. Mr. Murai lost his wife about 6 months ago. He looks scruffy and dirty, and is continuing to lose weight. He has not seen his doctor for over a year.

Vignette 3. Mr. Brown died about a year ago. You have noticed that Mrs. Brown missed church this week, although you talked to her the other day and know that she is not sick or out of town.

Vignette 4. Mrs. Garcia's husband has been dead for over a year, yet she continues to hide in her home, turning down all invitations. During today's visit, she talked again about the meaninglessness of life. She seems physically healthy, but appears sad.

Vignette 5. The Carters recently lost a child. They do not cry when you visit, but over the last few visits you begin to suspect that they are drinking heavily.

REFLECTIONS

- *Think about someone who experienced the death of a loved one. In your opinion, was the grief "normal" or "complicated?" What made it so? What helped this person through the grieving process? What role did you have in helping this person, if any? What could you have done better?*

- *If you have lost a loved one, would you say that your grief was "normal" or "complicated?" What helped you through the grieving process? What are your feelings now when you think back on this death?*

 Write your reflections here.

FINAL GIFTS: Creating a Meaningful Memorial Service

Death will come to all of us. Learning about options for funerals, memorials, and burial while we are alive makes good sense. What kind of service do you want? Does your family know your wishes? Will your wishes be honored after you die? What plans should you make now?

In this session, you will design a service that will be meaningful to you and to your loved ones, a service that expresses who you are and how you would like to be remembered. By going through this process, you may discover things you had not previously thought about. You may want to include your family and those close to you in the discussion. By planning for yourself, you will be better equipped to assist others who are dying and grieving.

Making plans before death occurs will help reduce the stress on surviving family members and loved ones at the immediate time of death. It would be helpful for them to know in advance what the deceased wanted in terms of a funeral or memorial service. And, because different services have different costs, deciding ahead of time can save you money as well as time.

At the end of this guidebook in the appendix, you will find helpful forms to assist you in getting your final affairs in order, as well as helping others. Although these guidelines will help you, remember to work within the framework of your faith. Ask your clergy person or spiritual leader for help in planning the service to determine which areas of the funeral or memorial service allow for personal expression. Some faiths have traditional ways of treating the dead and follow specific and structured protocols. Others are more flexible and allow for a greater sense of personal expression. Planning your memorial service with care and mindfulness is the final gift you share with those you love.

Now, I have no choice but to see with your eyes, so I am not alone, so you are not alone.

–Yannis Ritsos

A FUNERAL OR MEMORIAL SERVICE?

Funeral Service

A funeral is a traditional service that generally follows religious or cultural traditions and is considered formal. The body is present in most cases and there may be a viewing. A funeral usually takes place in a church, temple, or mortuary. Churches or family homes are less expensive sites for a funeral than a mortuary. If you choose to be cremated, you can have a funeral service prior to cremation.

Memorial Service

A memorial service can be as elaborate or as simple as you choose. Memorial services are held without the body and usually are less expensive than funerals because they require fewer professional services. A memorial service can be scheduled days or weeks after the death occurs, allowing time for family and friends to gather together. Sometimes family members and loved ones choose to hold memorial services simultaneously in different parts of the country, as the expense of travel during this time can be a burden on families. More than one memorial service may be held if the deceased was involved in various activities or work. The order of the service is flexible and untraditional, allowing for a greater expression of personal wishes and desires. Also, the idea of a memorial service in place of a funeral is becoming more popular as a way to celebrate the deceased's life. In this case, family and friends share their stories about the deceased, and the service tends to have an uplifting and positive focus.

Preparation of the Body

Embalming is a chemical treatment to temporarily preserve a life-like appearance. Funeral or memorial services with a viewing generally will require embalming, even if you choose cremation after the service. Embalming is rarely required by law. You have the right to forgo embalming if you choose direct cremation, immediate burial (within 30 hours of death), or refrigeration of the remains. Each state has different regulations, so check your local funeral or memorial society or Department of Health.

Service

Services may be held in a home, church, or mortuary. Ceremonies may follow the funeral service at the gravesite, mausoleum, or crematory chapel. Consult the funeral director or clergy about arrangements and costs.

Transportation

Often the body is transported in a hearse or special funeral home vehicle. Additional vehicles are needed to take the family to the services, burial ground, mausoleum, or crematory chapel.

Attendants

You may need to arrange for pallbearers, an organist, a soloist, clergy, drivers, burial attendants, etc.

Reception

A gathering at the family home or public place after the ceremony may be desired.

Perpetual giving up is the truth of this life.

–Rabindranath Tagore

Things to Consider for a Memorial Service

Service or Program

The tribute may include prayer, music, personal talks, and readings. The clergy member or principal speaker usually receives a small payment.

Reception

Family and friends may want to gather after the ceremony to continue to talk and comfort each other.

ACTIVITY: Planning a Meaningful Service

This activity will help you to plan your memorial or funeral service. Use this sheet to provide vital information and state your wishes.

I. PERSONAL INFORMATION

Name:

_____

Date of Birth:

_____

Place of Birth:

_____

Husband/Wife:

_____

Children:

_____

_____

_____

_____

Grandchildren:

_____

_____

_____

_____

Other Significant Persons:

_____

_____

_____

_____

III. THE SERVICE

A. Music I would like played or sung

List your favorite hymns, chants, or memorable songs you would like to have sung at your service. If you have any particular soloist, singers, or musicians that you would like to perform at your service, write them down as well.

1. _____

2. _____

3. _____

4. _____

B. Readings

Scripture, sutras, sacred readings, poems, etc. Write down who you would like to have offer each reading.

1. _____

2. _____

3. _____

4. _____

5. _____

C. Location of Service

❑ Church

_____

❑ Temple

_____

❑ Other

_____

D. Location of Gathering / Reception

❑ Church

_____

❑ Temple

_____

❑ Other

_____

Flowers and Monetary Donations

❑ Yes *(Which kind?)*

_____

❑ No

❑ I would like all monetary donations to go to my family

_____

❑ I would like a percentage of all monetary donations to go to the following organizations *(Which percent to each?):*

1. _____

2. _____

3. _____

F. Altar: How would you like the altar to be arranged?

Flowers *(Which kind?)*

_____

_____

My photograph *(How you would like to be remembered? Which photo best represents you? Where is it located?)*

_____

_____

Religious image *(What?)*

_____

Other

_____

_____

III. BURIAL INSTRUCTIONS

A. Burial or Cremation

I want to be *(check one)*

❑ Buried. If you own a plot, location of papers:

_____

_____

❑ Cremated

❑ Body Donation

❑ Other

_____

_____

B. Viewing

Would you like your body to be viewed at your service?

- ❑ Yes
  - ❑ Where should the viewing be held?

    _____
  - ❑ Which clothes would you like to wear?

    _____
- ❑ No Viewing

I have pre-arranged my funeral and burial

- ❑ Yes *(with which mortuary?)*

  _____
  - ❑ Location of plan:

    _____
- ❑ No

Person in charge at time of need: _____

_____

Phone: _____

IV. Other Instructions or Information

_____

_____

_____

_____

_____

_____

He who binds to himself a joy does the winged life destroy. But he who kisses the joy as it flies lives in eternity's sun rise..

–William Blake

REFLECTIONS

Recall the most memorable memorial or funeral service you have attended. What made it meaningful?

Recall the least memorable memorial or funeral service you have attended. What made it so?

 Write your reflections here.

FINANCING YOUR FUNERAL

Funerals are a great expense, third only to the purchase of a house and automobile. This expense can be made worse when the ones making the arrangements have little knowledge of their rights or alternatives. This section will help you to understand the benefits and dangers of prepaying your funeral, the importance of planning ahead financially, and where to find assistance in this time of need.

Preplanning

People should always preplan and consider ways to pay for the expense of a funeral. Preplanning saves your survivors from the stress of making choices in a time of grief, and also allows you to compare prices and make informed choices about which type of service you desire. You may want to join a local memorial society. These are non-profit organizations dedicated to the ideal of affordable funerals and preplanning. For more information, contact your local funeral or memorial society.

Should I Prepay?

The answer to this question depends on your financial situation, your desire to handle your own arrangements, and where you live. The laws that protect consumers in regards to preneed insurance and preneed trust plans differ from state to state. There are advantages and drawbacks to paying for a funeral in advance. Therefore, you should be sure that you fully understand the contract before signing it. You need to maintain control over your funds so there will be adequate money to finance your funeral when the time comes and to confirm that your money is protected.

It is easy to get confused with all of the different terminology surrounding prepayment: prepay, preneed, prearrange, preplan. There are no set definitions for each of these terms, but generally prearrange and preplan simply mean stating your wishes in writing or verbally, without prepaying for those arrangements.

Prepaying can mean setting aside funds ahead of time for final arrangement expenses. Preneed, however, is a special type of prepayment. Preneed is a term used by the funeral industry to describe plans and trusts that are sold to consumers by funeral homes, cemeteries, and insurance agents.

Examples of Prepayment Methods

Pay-on-death account. This is an individual savings plan or trust that is set aside for one's funeral/burial. While alive, the account holder has complete control over the funds and can make transactions at any time. A sum of money equal to today's funeral/burial costs is put aside, in the form of a certificate of deposit or other form, payable to a beneficiary of choice. Upon death, these funds will be immediately available to the beneficiary.

Regular life insurance. With regular life insurance, generally a family member is designated as the beneficiary. That family member can use part of the money to pay for funeral and burial costs. Life insurance allows survivors to purchase the merchandise and services they want without actually paying the cemetery or funeral home ahead of time.

Bank trust. In a bank trust fund, you can designate a beneficiary of the trust upon your death, which could be a family member or a funeral home. If you set up a "revocable" trust, you can remove the money at any time. But if the trust is "irrevocable," no one, not even you, can use the funds for any purpose other than what is stated.

Regulated trusts. Nearly all states have regulated trust laws that provide provide for consumer protection. Most States require 100% trusting and do not leave money in the hands of the mortician. Unless designated as "irrevocable," individual savings and regulated trusts are subject to claim by the state if you receive social benefits. All states, except Alabama, Vermont and the District of Columbia, regulate the sale of commercial trust agreements. State laws may vary. Check your local funeral or memorial society for accurate and up-to-date information.

Insurance-funded plans. Life insurance or an annuity contract may include a death benefit that accounts for inflation. Such insurance is often sold by morticians with the expectation that they are named the beneficiary. Other plans are simply life insurance plans, and you can choose who will be named to control the funds.

Important Questions If Prepaying with a Funeral Home

Before you prepay for a plan with a funeral home, make sure you understand the answers to these questions:

1. What happens to the money I prepay? (Make sure you get official documentation of where your funds are put.)
2. How much time do I have to change my mind and receive a full refund?
3. What happens to my money if the funeral home goes out of business or changes ownership?
4. What happens if I die away from home, on vacation for example?
5. Even if I do prepay for the funeral plan, which expenses will my survivors have to pay for later? What isn't covered? (Remember, the sales tax payable at the time of death is not factored into the prices quoted.)

Advantages of Prepaying

By paying for your arrangements in advance you may:

- Insure that there is money available to pay for your service and burial.
- Provide peace of mind if you have no survivors to make the final arrangements for you.
- Prepaid plans are considered separately if you apply for certain benefits such as Medicaid. Any amount over $1,500 is considered part of your assets (a burial plot for yourself is exempt, however). Dedicated funds, as long as they are irrevocable and payable upon death, are considered as a funeral plan and are not considered as part of your assets.

It's not how much you do, but how much love you put into the action.

–Mother Theresa

Drawbacks to Prepaying

There are disadvantages of paying for funeral expenses in advance. Funeral homes that change ownership may not honor contracts with former owners. If you need to cancel or change the plan, part of the money may not be refunded. Some additional concerns:

- If you move, some contracts can be transferred, but you may be charged a transfer fee.
- If you want to cancel your plan, you may be charged a cancellation fee, or a percentage of your funds may be kept by the funeral home.
- The amount of money you pay today may not cover future funeral costs, resulting in either the substitution of less expensive merchandise or additional payments by survivors.
- If you pay money now for funeral arrangements, you will not have that money to use for other possible emergency expenses.

Financial Assistance

Financial assistance is often available from trade unions, credit unions, or fraternal organizations. Insurance can be applied toward funerals in some cases. Social Security may contribute toward funeral costs if certain requirements are met. The Veterans Administration may help pay for a veteran's funeral, and offers free burial in a national cemetery. You may consider joining your local memorial society for assistance. Often they can help you in planning your funeral and locating funeral directors with reasonable prices.

Supplemental Security Income (SSI)

If applying for SSI, you can set aside up to $1,500 for burial expenses and it will not be counted as an asset. This money must be specifically put aside for burial expenses and must be set apart from other resources. If you use any of the burial funds for other purposes, your future SSI payments will be reduced by that amount. This does not mean that you have to put the $1,500 in an irrevocable trust, but only that it is set aside. Insurance policies with a face value of less than $1,500 are also exempt. Other exemptions include burial space items, such as a casket, burial plot, vault, and headstone or marker.

Some Final Notes

Planning for your funeral in advance is the best thing you can do. Comparing prices is a good idea for any purchase you make, especially funerals. Yet you should be cautious about paying for your funeral in advance. It is always possible that you may change your mind about your plans, move, or the funeral home may go out of business before it can provide the service you pre-paid for. Any of these situations may cause you to lose some or all of your money. Make sure you understand fully the contract you are signing, to protect yourself from any possible losses.

Plans are useless,
but planning is invaluable.
– Winston Churchill

ACTIVITY: Planning Ahead

Break up into groups of 3 to 6 people to discuss these questions:

- How many have planned or payed in advance for their funeral or burial? Why were these plans made? What was arranged?
- How many have made final arrangements for others? Were the arrangements discussed with those people before death or were decisions made after death? Why? What happened?
- If it was an "immediate need" experience where final arrangements had to be made quickly, what was the outcome?

REFLECTIONS

1. *Is it difficult for you to talk about your final wishes with your family? If so, why?*

2. *Do you feel that it is "bad luck" to plan in advance for your death or to express your wishes?*

3. *Have you ever had to make arrangements for someone else? If so, what would have made it easier? What was most difficult?*

 Write your reflections here.

PUTTING AFFAIRS IN ORDER

After a death, there is an overwhelming amount of paperwork that needs to be completed. Survivors are often at a loss for how to proceed. Following the final services, this checklist can help survivors navigate their way.

Notify the Lawyer and/or Executor of the Estate

Settling an estate can be a complicated affair. There often will be a need for legal advice on matters such as:

- Re-recording of property deeds
- Disposition of stocks and bonds, investments, savings and checking accounts
- Disposition of business assets
- Conservation and disbursement of the deceased's estate

Obtain Certified Copies of the Death Certificate

You will need a certified copy of the Death Certificate every time you apply for benefits or need proof of the death. Get at least 10 certified copies, depending on the complexity of the estate. Photocopies will not work. Fees vary state to state. Some states offer discounts for additional copies ordered at the same time. These can be obtained in person or by mail from the Vital Statistics Branch of the State Department of Health. Most funeral homes offer this service to you for the same fee.

Obtain a Copy of the Marriage Certificate

If you are the spouse, you may need to show proof of marriage before you can inherit from the estate, existing policies, and investments. You will also need proof of marriage when applying for Social Security and other benefits.

Contact the Local Life Insurance Agent or the Home Office of the Life Insurance Company.

Check all life insurance policies for death benefits. You will usually need to show 2 documents: a Death Certificate and a statement of claim. Companies reserve the right to request further information. Claims should include the policy number(s) and face amount(s); full name and address of the deceased; the deceased's date and place of birth; the date, place, and cause of death; the deceased's occupation and date last worked; and the claimant's name, age, address, and Social Security number.

Contact the Local Social Security Office

Contact the Social Security office to check eligibility for lump-sum death benefits (currently $255) and to inquire about monthly benefits for the surviving spouse. Make sure you have the Social Security number of the deceased and anyone who may be inheriting from the estate. Remember, you must apply for Social Security benefits. They are not automatic. Delays in applying may result in the loss of certain benefits. You will need to bring:

- A certified copy of the Death Certificate
- The deceased's Social Security number
- Approximate earnings of the deceased in the year of death
- Employer's name (if employed)
- Record of earnings in the year prior to death (W-2 form or tax return)
- Marriage certificate
- Social Security numbers of surviving spouse and dependent children
- Proof of age of the surviving spouse and dependent children under age 23 (birth certificates)

Explore Eligibility for Civil Service Benefits

Survivors of civil service or federal workers may be eligible for benefits if the deceased was the spouse and he/she died after 18 months on the job. For details, contact the Civil Service Bureau of Retirement, Insurance, and Occupational Health, 1900 E. Street, NW, Washington, D.C. 20415.

Notify Organizations, Churches, and Clubs Where the Deceased Was a Member

Contact service organizations, clubs, and professional organizations the deceased belonged to. Survivors may be eligible for benefits. Many of these organizations offer life insurance policies at reduced rates, may return any unused portion of annual dues, or may have special funds for families in need of financial help.

Locate Military Discharge Papers

If the deceased was a veteran, contact the nearest Veterans Administration office to determine funeral benefits. If you need to obtain verification, write to the Department of Defense, National Personnel Record Center, 9700 Page Blvd., St. Louis, MO 63132.

Locate Accounts, Funds, etc. Held Jointly.

ACTIVITY: Where are your Vital Documents?

Name: _____ Date: _____

ESTATE RELATED	LOCATION OF DOCUMENT
Will	
Trusts	
Other	

INSURANCE	LOCATION OF DOCUMENT
Life	
Health	
Disability	
Automobile	
Other Policies	

DEEDS/TITLES/CERTIFICATES	LOCATION OF DOCUMENT
Automobile	
Birth Certificate	
Marriage License	
Death Certificates	
Property Deeds	
Other	

FINANCIAL INVESTMENTS	LOCATION OF DOCUMENT
Certificates of Deposit	
Mutual Fund Records	
Stocks/Bond Certificates	
Other Investments	

CHECKING/SAVINGS ACCOUNTS	LOCATION OF DOCUMENT
Checking *(name of institution/acct.)*	
Savings *(name of institution/acct.)*	
Other	

TAX RECORDS	LOCATION OF DOCUMENT
Last Year's Tax Return	
Last 7 Years of Tax Records	
Other	

RELIGIOUS AND CULTURAL TRADITIONS IN MOURNING

In many of our communities, we can see many different religious and cultural expressions of mourning. It is important to learn about and respect differences, as you may be called upon to assist a bereaved person who follows a different faith or comes from a different culture than you do. Mutual respect helps keep our personal beliefs and biases from becoming barriers to compassionate and effective ministry.

Remember, there is no universally accepted "right" way to mourn a loss. The goal of grieving is to come to an acceptance of the death and have a reemergence of hope. There can be many paths to this goal.

One word frees us from all the weight and pain of life... that word is love.

–Sophocles

Rituals Associated with Mourning

Rituals are acts or ceremonies that have significant meaning attached to them. Rituals of mourning, such as funeral services and burial rites, allow us to acknowledge and process our grief.

Death rituals can help us in many ways:

- They help us to deal with our grief at a time of loss.
- They help us release the person who has died.
- They allow us to reflect on the past, deal with the present, and look to the future.
- They help bind us together with other mourners, allowing for a possibility to share common feelings and thoughts.

Many rituals related to death are sanctioned by and performed by faith communities. People outside of faith communities also can benefit from ritual, and should be encouraged to create their own if nothing else exists for them.

Love bears all things, believes all things, hopes all things, endures all things...

Love never fails..

–St. Paul

Common Rituals

Although there is variation within each denomination, common themes and practices related to death and bereavement are important to keep in mind.

Buddhist

Many Buddhist sects (except Pure Land) incorporate the notion of successive births, or reincarnation. After death, people enter a 49-day intermediate stage until they take on another life form. Following the death, then, the filial family will hold services every 7th day for 7 weeks over this 49-day period. Observances also are held on the 100th-day after death and on the 1-year and 3-year anniversaries. Many Buddhist denominations observe additional anniversaries for individual ancestors and honor all ancestors during certain seasons. Some Buddhists also maintain ancestor shrines in their homes. In return, the ancestral spirits will watch over and protect their descendents. Most Buddhists prefer cremation to burial.

Christian

Every Christian denomination has specific prayers and services for the deceased. Catholics hold a 9-day Novena, which ends with a large feast. The Rosary is said, as well as other prayers, including the 23rd Psalm and other psalms and scriptural readings that provide comfort. Burial is common, although cremation is becoming more popular. All Saints Day, celebrated on November 1 of each year, serves to acknowledge and pray for the souls of the dead. Protestant denominations do not generally hold post-funeral services but may acknowledge the deceased on certain days, such as Memorial Day or Veterans Day.

Hindu

If the dying person is unconscious at the moment of death, a family member chants a mantra softly in the right ear. Holy ash or sandal paste is applied to the forehead, Vedic verses are chanted, and a few drops of milk or holy water are trickled into the mouth. Under no circumstances should the body be embalmed or organs removed for use by others. The rites are led by the "chief mourner" (the eldest son in the case of the father's death and the youngest son in the case of the mother's). Only men go to the cremation site, led by the chief mourner. On the 3rd, 5th, 7th or 9th day, relatives gather for a meal of the deceased's favorite foods. Also observed are the 1-month and 1-year anniversaries.

Islamic

As death nears, the patient and loved ones may recite a certain chapter from the Qur'aan. After death, the body is washed and shrouded in simple white cloth. The deceased may be viewed, but it is not customary to hold a wake, make up the face, or dress the deceased in street clothes. Cremation is unacceptable. After the burial, people gather at the house of the deceased or in the mosque to recite from the Qur'aan and to say prayers for the dead. In some families, this event will be repeated on one or more occasions until the 40th day after burial and then yearly.

Jewish

Jewish burials take place as quickly as possible, following the principle of honoring the dead. Jewish funerals are very simple. Before they begin, the immediate relatives of the deceased -- siblings, parents, children, spouse -- tear their garments to symbolize their loss. Sometimes the rabbi will tear his garments and recite a blessing. During the ceremony that follows, Psalms are recited, then a eulogy and El Maleh Rachamim, the memorial prayer. "Shiv'a" refers to the 7-day mourning period that begins immediately after the funeral. During this time, mourners sit with their grief, remembering, weeping, dreaming, telling stories, and sharing memories. Jewish law requires that the immediate family spend this week in formal mourning, and other relatives and friends sometimes join them. Although 7 days may sound like a long time to "sit," in practice the 7 are more like 5 because fractions of days are considered full days. Thus, the day of the funeral is counted as the first day of shiv'a, even if the burial occurred in the afternoon. Likewise, shiv'a ends on the morning of the seventh day — traditionally, right after shaharit, the morning prayer service.

The garden of Love is green without limit and yields many fruits other than sorrow and joy. Love is beyond either condition: without spring, without autumn, it is always fresh.

–Rumi

ACTIVITY: Rituals in Your Culture or Religion

Divide into small groups of 5 or 6. If yours is a multicultural and/or multi-religious group, try to have persons from different cultures and/or religions represented in each group. Discuss the following questions:

- Which kinds of rituals surrounding death and grieving do you remember from your childhood?

- What does your culture or religion specifically do that is helpful to the grieving process before and after a death occurs?

- In which ways are your cultural or religious rituals different from others? In which ways are they similar?

- If you lost a loved one, would you follow any rituals from your culture and/or religion? If so, which ones? If not, why not?

REFLECTIONS

What memories do you have of how your parents or grandparents drew from their culture and/or religion to help comfort people in times of grief?

Think about the cultural and religious rituals surrounding death and burial. What do you find most comforting in these rituals? Do you feel they are being lost over time? What things are important to pass on to the next generation?


Write your reflections here.

"DIFFICULT" DEATHS

Sometimes I go about in pity for myself, and all the while, a great wind is bearing me across the sky.
–Ojibwa poem

Every death is difficult. But some deaths are more difficult than others. Consider this: most people want to die in old age, with their minds intact, and free from pain and suffering. But not all deaths are like this. Although no death is easy, people may feel more confused or unsettled if:

- The death is "off-time," for example, the death of a young child or the death of a child (even an adult child) that precedes the death of the parent.
- The death is due to suicide.
- The death they are grieving is due to miscarriage or abortion.
- The death is associated with a disease that is feared or shameful to a particular culture or religion, such as AIDS, cancer, or mental illness.
- The death is sudden or unexpected.

Death of a Child

The emptiness brought about by the loss of a child is tremendous. Children are not expected to die before their parents. With the loss of a child comes the loss of hopes and dreams for that child, the loss of the parental role, and the loss of that child's love. There is often "survival guilt," and surviving parents may feel that they should have died instead of the child. The relationship between the parents often suffers, as parents may not know what to say to each other or how to express the depth of their loss. They may avoid discussion and become isolated from each other.

The surviving siblings of the deceased child may be affected in similar ways. They may feel guilty to still be alive, they may withdraw, or they may feel isolated from the parents who are lost in their own grieving. They may also experience over-protection by parents who "don't want to lose another child."

Parents whose infant died from Sudden Infant Death Syndrome (SIDS) often fear they might have done something wrong or did not care for the infant in the proper way. If the death is not discovered right away, there may be the appearance of "bruises" caused by the pooling of blood. This might appear to other family members as if someone hurt the baby. Abuse may be suspected. All of these factors can place extreme stress on the surviving parents and family members.

Death Due to Miscarriage or Abortion

Most faiths recognize the sanctity of life and teach that the deliberate taking of a life is a sin. To some, abortion is paramount to murder and against the precepts of their faith. Despite these teachings, abortion is commonly practiced today. Many US-born people feel that abortion is a matter of personal choice, even though families may not openly discuss it. Within a faith community, however, those contemplating abortion may not seek assistance or guidance for fear of judgment by the community and by God.

A miscarriage is the unintentional loss of a fetus. Although still tragic, miscarriage carries less stigma than abortion. Some people view miscarriages with a bit of fatalism and say, "If you miscarry, it means that this birth was not meant to be." Still, the death of a fetus can cause great sadness, and parents may mourn the loss of a child that could have been. Special rites to mark a miscarriage may be comforting to survivors.

Every stroke of my brush is the overflow of my inmost heart.
–Sengai

Death from Suicide

A death by suicide is tragic and often unexpected. Death from suicide often represents a conflict with religious or cultural values. When it occurs within a faith community that is ill equipped to embrace it, the burden on survivors may be unbearable. Families may want to hide the suicide from others, or they may offer another "explanation" for the death because they fear further pain from chastisement. It is common to avoid the topic in conversation and possibly even hide it from other family members, such as younger children or relatives. Some survivors may blame themselves for not seeing the "signs" quickly enough, or for not having provided the love and support that they believe might have prevented the death. Other survivors may feel anger toward the deceased. With this jumble of feelings, survivors need special consideration, rather than "punishment" for the acts of the deceased.

Sudden Death

Grieving a loss of a loved one as a result of sudden death is extremely difficult. Survivors may have difficulty coping after the shock of the death has worn off. They may have intense emotions such as anger, guilt, confusion, helplessness, and loss of control. The survivor's world has radically and abruptly changed. Feelings of unpredictability can leave survivors feeling anxious and vulnerable. The grieving process may take longer to complete, as feelings and thoughts are intensified. In addition, if the mourner was unable to view the body to confirm the death, other complications can arise. Many cultures consider sudden, unexpected, or traumatic death to be "bad news." Religious and cultural rituals, therefore, play an important part in the grief process by acknowledging the death and providing healing and closure for the bereaved.

Mentioning the Unmentionable

Faith communities are places of love, sanctuary, and support. But some faith communities may not know how to best help survivors of "difficult" deaths. There may be strong feelings and beliefs that influence the way in which care is given. If one is taught, for example, that homosexuality is a sin, how do we compassionately and lovingly deal with a death due to AIDS of a family member who was homosexual? If it is believed that the individual who has taken his/her life by suicide will be eternally separated, how can we provide words of comfort and reassurance?

We fear we may say the wrong thing. More often, we do not know what to say that could be helpful. As those who assist survivors who have lost a loved one from such a death, we may be reluctant to talk about this death.

As compassionate caregivers, however, we must create an environment that puts an end to the silence and judgement surrounding these types of deaths. Those in caregiving ministries who have strong negative feelings about any of these kinds of deaths should meet with a counselor or clergy person to discuss these issues.

All for love, and nothing for reward.

– Edmund Spenser

ACTIVITY: Case Discussion

Divide into groups of 2 or 3 to examine your religious, cultural, and personal beliefs associated with these "difficult" deaths and how they might affect your ability to help the survivor.

Vignette #1. The deceased died in childhood.

1. What are your religious, cultural, and personal beliefs associated with this "difficult" death.
2. How might these beliefs affect your ability to help the survivor?

Vignette #2. The deceased died of AIDS.

1. What are your religious, cultural, and personal beliefs associated with this "difficult" death.
2. How might these beliefs affect your ability to help the survivor?

Vignette #3. The deceased committed suicide.

1. What are your religious, cultural, and personal beliefs associated with this "difficult" death.
2. How might these beliefs affect your ability to help the survivor?

Vignette #4. The deceased died suddenly and unexpectedly.

1. What are your religious, cultural, and personal beliefs associated with this "difficult" death.
2. How might these beliefs affect your ability to help the survivor?

THE COMPASSIONATE CONVERSATION

All humans grieve when they lose a loved one. A person's religious or cultural tradition may give structure to how grief is expressed and may provide a timeline for mourning. But the majority of people who lose a loved one will also need to talk about their loss. As a helper, you need to become skilled in the art of conducting the Compassionate Conversation.

There are 5 steps to a Compassionate Conversation:

Stop

When a bereaved person wants to share something with you, stop what you are doing and give him/her your undivided attention.

Look

Look at the person you are listening to, and be at the same eye and body level.

Listen

Listen from the heart. Focus your attention on what the person is saying and listen without judgement. Do not talk just to talk. Do not try to solve the bereaved person's problems.

Respond

Respond in ways that validate, clarify, and extend the conversation. As the helper, your job is to get the survivor to talk. Thus, your responses should lead to further sharing.

Maintain Confidentiality

Do not share what you've heard with others. Keeping confidentiality is essential for helpers in all professions. It protects the individual you are helping and increases the level of trust between you.

When Silence speaks for Love, she has much to say.
–Richard Garnett

More Detail on Each Step

Stop

Focus on the person only. Give your entire attention and presence to what the person is saying and doing. Don't allow distractions. Try to find a place away from noise, telephones, pagers, or interruptions.

Don't have an agenda. Do not decide what the outcome should be ahead of time. Do not try to move the conversation in a particular direction. Allow the survivor the "leading role" in the conversation. Remember, this is his/her journey, not yours.

Do not use this time to do your own grief work. Take inventory of what is happening within you as you listen and attend to the bereaved. Always address your own issues outside of the caring relationship.

Look

Look at the person you are listening to, and be at the same eye and body level. This means, if the person is sitting, you sit too. This increases comfort. Pay attention to your body language and make sure you are sending a message that the bereaved has your undivided attention.

Again, do not use this time to think about your own problems. If you are distracted, it will show in your face or body language. Pay attention to the bereaved person, not to your own thoughts and feelings.

Listen from the Heart

One of the most valuable gifts we can give to someone who is grieving is simply to listen. Often we feel we must say or do something, but this can rob the bereaved of an opportunity to express his/her feelings and heal him/herself. We cannot take away the pain of another through the offering of words or by our good intentions. We can, however, "listen from the heart" as the bereaved talks through his/her grief.

As a helper, your job is to create a safe and comfortable environment for the survivor to talk. Thus, your responses should lead to further sharing.

When we "listen from the heart" we:

- Demonstrate in words and body language we are ready and willing to listen.
- Feel comfortable in the presence of anger, guilt, sorrow, and blame.
- Do not personalize the feelings. Even if the bereaved seems to express anger at you, do not take it personally.
- Refrain from silencing the bereaved.
- Feel comfortable with our own silence.
- Feel comfortable with the self-inquiry that accompanies grief.

What soap is for the body, tears are for the soul.

–Jewish proverb

Respond in Ways That Validate, Clarify, and Extend the Conversation

It is difficult to refrain from talking. We see ourselves as "helpers," and we want to help by talking and trying to make things better. In Compassionate Conversations, however, we must learn to respond in ways that validate, clarify, and extend the conversation. Try to:

- Validate that the bereaved person's feelings are common expressions of grief and that there is nothing "wrong" with the bereaved for having these feelings.
- Restate what you've heard, felt, or seen.
- Ask an open-ended question that will lead to more sharing. An open-ended question is one that cannot be answered with a word or 2, but requires a longer answer.
- Do not personalize the feelings expressed to you.
- Do not make judgments on what you hear, even if it goes against your own religion, culture, or personal beliefs.
- Refrain from trying to "fix" things.
- Refrain from telling the bereaved what to do.
- Refrain from telling the bereaved what you would do in this situation.
- Assure the bereaved that you are there for him/her.

Above all, don't give meaning to another's experience. Do not interpret the death or the grief according to your values and beliefs. As you support and value all viewpoints, your caring presence brings unity instead of diversity.

Here are some examples of responses that validate, clarify, and extend the conversation:

Validating

"It is normal to have these feelings when you lose a loved one."

"It is not unusual to feel that way."

"If this happened to me, I would feel sad too."

Restating What You Hear, Feel, and See

"You sound angry."

"I hear sadness in your voice."

"I'm not sure, but it sounds like you might feel some shame about the way your loved one died."

"It sounds like you miss your loved one very much."

"You're up early. How are you sleeping?"

"I notice that you haven't eaten."

Asking Open-Ended Questions

"What are you feeling now?"

"Which kinds of things worry you?"

"What can I do to help?"

Maintain Confidentiality

Confidentiality is an essential component of any intimate and trusting relationship. What is experienced within the context of the caring relationship should not be discussed with others. Hold what is said to you in confidence unless there is a clear indication that the person may harm him/herself or others. Then speak to your clergy leader about your concerns. Confidentiality builds the trust necessary to continue Compassionate Conversations.

When we are no longer able to change a situation, we are challenged to change ourselves.

–Viktor Frankl

Where to Have a Compassionate Conversation

Compassionate Conversations, in which you "Stop, Look, Listen, Respond, and Maintain Confidentiality" can take place anywhere. Be prepared to have a Compassionate Conversation on the phone, on the bus, in church after the service, or anywhere. Never force a bereaved person to talk. But if the bereaved person wants to talk, encourage it, wherever and whenever he/she feels like it. Oftentimes, however, a Compassionate Conversation will take place in the home or in a safe, home-like setting.

Practice Makes Perfect

You may find it difficult at first to hold a Compassionate Conversation. This may be your first experience trying to "Stop, Look, Listen, Respond, and Maintain Confidentiality." We have been trained to offer words of comfort and suggestions toward healing. Until the art of listening becomes natural, we may feel uncomfortable or incompetent. It takes courage to trust that, in the face of silence, the bereaved can process his/her questions and find his/her own solutions. No matter how grave and despairing the words of the bereaved may sound, or how uncomfortable the feelings that surface, behind the words new insights are emerging. The gift we give through listening and responding appropriately allows another to work through his/her sorrow, fears, and pain. Both our listening and our responses should be attentive and loving.

Barriers to Compassionate Conversations

Our own feelings can prevent us from truly "listening from the heart." These may include our own fears, guilt, anger, or unresolved grief. Listening to the bereaved person's pain and sadness may trigger unresolved feelings within you. If you are not able or allowed to express your own pain, this can become a significant barrier. When you are preoccupied with your own concerns, you cannot be present to genuinely listen from the heart.

What to Do

Personal issues that arise for "listeners" should be addressed outside of the caregiving situation. Do not inflict them on the bereaved! Identify safe places to discuss and resolve your own feelings, for example with family, friends, your pastor, a psychologist, or with other lay ministers.

Seeing into darkness is clarity... This is called practicing eternity.

– Lao-Tsu

ACTIVITY: Compassionate Conversations

Divide into groups of 3. One person is to play the role of the bereaved person or "survivor," the second is the "listener," and the third is the "witness."

Instructions

"Survivor"—You have just lost a loved one and are grieving. The "listener" has come to visit you and you decide to share your feelings, questions, and concerns with this person.

"Listener"—Practice your skills at conducting a Compassionate Conversation (listen from the heart and respond in ways that extend the conversation).

"Witness"—Watch the interaction and be prepared to provide feedback to the others, including feedback on subtle gestures and body language.

Continue this activity for about 3 minutes, or until the facilitator signals you to stop. Then, offer your observations. Use these questions as a guide.

"Witness"—What did you notice about the "survivor" and the "listener?" How did the "survivor" express his/her grief? Was the "listener" able to hold an effective Compassionate Conversation? Which spiritual or cultural issues emerged?

"Survivor"—How did it feel to talk to someone else about your grief? Did you feel comfortable or anxious? Did the "listener" do anything that made you feel more comfortable? Less comfortable?

"Listener"—What did you notice about the "survivor." How successful do you feel you were at holding a Compassionate Conversation? What would you do differently next time?

Switch roles and repeat.

APPENDICES

OBITUARY INFORMATION GUIDELINES

The following information may be helpful to write an obituary notice. It is helpful for the family to write this together.

Name: _____

Age: _____

Date of Death: _____

Cause of Death: _____

Date of Birth: _____

Place of Birth: _____

Preceded in Death by: _____

SURVIVORS

Spouse/Partner's Name: _____

Parent's Name: _____

Children's Names: _____

Their Spouses: _____

Grand Children & Great GrandChildren: _____

_____

Sisters & Brothers: _____

Others: _____

Religious Affiliation: _____

_____

Education (College or University): _____

_____

Military Service: _____

_____

Employment: _____

_____

_____

Lodge or Club Memberships: _____

_____

_____

Accomplishments & Honors (What you would like to be remembered for): _____

_____

_____

Pallbearers (optional): _____

_____

_____

Other newspapers to send information to: _____

_____

_____

PERSONS TO BE NOTIFIED IN CASE OF DEATH

Name _____ Phone #: _____

Address: _____

_____

Relationship: _____

Name _____ Phone #: _____

Address: _____

_____

Relationship: _____

Name _____ Phone #: _____

Address: _____

_____

Relationship: _____

Name _____ Phone #: _____

Address: _____

_____

Relationship: _____

Name _____ Phone #: _____

Address: _____

_____

Relationship: _____

Name _____ Phone #: _____

Address: _____

_____

Relationship: _____

Name _____ Phone #: _____

Address: _____

_____

Relationship: _____

RECORD OF INDIVIDUALS/GROUPS PROVIDING ASSISTANCE

A record of those providing help during the funeral or memorial service.

NAME	ADDRESS	PHONE

GENERAL ASSISTANCE

HOUSE SITTING/CHILDCARE/TRANSPORTATION

FOOD SERVERS

OTHER

BEREAVEMENT SUPPORT INFORMATION SHEET

Name of Survivor: _____

Name of Deceased: _____

Date Deceased: _____

Cause of Death: _____

Circumstances Related To Death: _____

_____

Telephone: _____

Address: _____

_____

Significant Survivors: _____

_____

Place of Burial or Disposition of Ashes: _____

_____

Deceased's Birthday: _____

Wedding/Anniversary: _____

Primary Survivor Birthday: _____

Special Circumstances: _____

_____

Pastoral Care Person(s) _____

_____

Telephone: _____

E-Mail: _____

WEB SITES WITH END-OF-LIFE RESOURCES

PAIN RESOURCES

1. **American Alliance of Cancer Pain Initiatives.** AACPI promotes cancer pain relief nationwide by supporting the efforts of State Cancer Pain Initiatives, which are voluntary, grassroots initiatives providing education and advocacy to health care providers, cancer patients, and their families. **www.aacpi.org**

2. **American Pain Foundation.** A nonprofit, online information resource and patient advocacy organization, their mission is to improve the quality of life of people with pain by providing practical information for patients, raising public awareness and understanding of pain, and advocating against barriers to effective treatment. **www.painfoundation.org**

3. **Department of Pain Management and Policy, Beth Israel Medical Center.** Easy-to-understand, useful resources for clients, caregivers, and professionals. Includes a pain library, online support groups, and an "Ask the Doctor Section." **www.stoppain.org.**

CAREGIVER RESOURCES

1. **AXA Foundation Family Care Resource Connection.** Hosted by the National Alliance for Caregiving this site includes an index and rating of a wide range of consumer books, videos, web sites, training programs, newsletters, and other valuable materials. **www.caregiving.org/content/fcoc.html**

2. **Hospice Net.** This well-written, easy-to-navigate site, includes a wealth of information on hospice services, bereavement, and caregivers. **www.hospicenet.org.**

3. **Partnerships for Caring.** A national organization to improve end of life care, they have state-specific advance directives. **www.partnershipforcaring.org**

BEREAVEMENT

1. **Compassionate Friends.** This is a national nonprofit, self-help support organization for bereaved parents, grandparents, and siblings following the death of a child. They also provide information to others who want to be supportive. **www.compassionatefriends.org**

2. **Hospice.** Your local hospice will have support groups and bereavement services. **www.hospicenet.org**

WHAT ARE OTHER STATES DOING?

1. **Center for Ethics in Health Care at Oregon Health and Science University.** They have been leaders in Oregon's efforts to improve end-of-life care.. Background information on Oregon's coalition, evaluations on ongoing efforts, and an excellent resource list are available at **www.ohsu.edu/ethics.**

2. **Missoula Demonstration Project.**
   Visit **www.missouladem onstration.org** to learn about how an entire community has mobilized to improve end-of-life care. Especially interesting is their story-telling project and school outreach.

National Organizations

1. **Community State Partnerships.** A Robert Wood Johnson Foundation program administered by the Midwest Bio-Ethics Center. Check with them for contact information for your local coalition. **www.midbio.org/npo-statepage.htm.**

2. **Last Acts.** This national coalition of organizations is working to improve care and caring near the end of life. Visit **www.lastacts.org** to identify coalition partners in your state, and learn how to become a partner in the Last Acts Campaign. The site has articles, brochures, a book and music shop, and helpful links.

CONSUMER INFORMATION

1. **Funeral Consumers Alliance.** Dedicated to a consumer's right to choose a meaningful, dignified, affordable funeral. FCA offers state specific information as well as providing a wealth of information for consumers, unique links, and a tasteful humor section. They can be found at **www.funerals.org.**

POLICY RESOURCES

1. **American Bar Association Commission on Legal Problems of the Elderly.** ABA provides information on end-of-life law and legislation. **www.abanet.org/elderly/home**

2. **"State Initiatives in End-of-Life Care"** are a series of policy briefs from Midwest Bio-Ethics and Last Acts, including a 4-part series on long-term care reform and examples from Oregon's experiences. **www.midbio.org/npopolicybrief.htm**

3. **University of Wisconsin Pain and Policy Studies.** This site includes a variety of policy analyses, including an annual review of state pain policies. **www.medsch.wisc.edu/painpolicy.**

STATE OF THE ART PROJECTS

1. **"Promises to Keep: Changing the Way We Provide Care at the End of Life"** is a publication describing institutions and organizations from around the United States that have demonstrated excellence in end-of-life care. Available on the National Coalition on Health Care Web site at **www.nchc.org.**

2. **"Promoting Excellence in End-of-Life Care Interim Report."** This national program is sponsored by the Robert Wood Johnson Foundation to establish demonstration projects to "advance health care systems and institutions to improve care for dying patients and their families." Available at **www.promotingexcellence.org.**

BIBLIOGRAPHY

Andrews, F. (1991). *The Art and Practice of Loving.* New York: Tarcher/Perigee.

Bernat J.L. (2001). Ethical and legal issues in palliative care. *Neurology Clinics, 19* (4), 969-87.

Braun, K.L., Pietsch, J.H., & Blanchette, P.L. (2000). *Cultural issues in end-of-life decision making*. Thousand Oaks, CA: Sage Publications.

Byock, I. (1997). *Dying well: The prospect for growth at the end of life.* New York: Riverhead Books.

Carlson, L. (1998). *Caring for the dead: Your final act of love*. Hinesburg, VT: Upper Access.

Cassell, E.J. (1991). *The nature of suffering and the goals of medicine*. New York: Oxford University Press.

Field, M.J. and Cassel, C.K. (1997). *Approaching death: Improving Care at the end of life.* Washington, DC: National Academy Press.

Council on Ethical and Judicial Affairs, American Medical Association (1992). Decisions near the end of life. *Journal of the American Medical Association, 276*, 2229-2233.

Council on Scientific Affairs, American Medical Association (1996). Good care of the dying patient. *Journal of the American Medical Association, 275,* 474-478.

Cummins, R.O. (1992). Matters of life and death: Conversations among patients, families, and their physicians. *Journal of General Internal Medicine, 7*, 563-565.

de Hennezel, M. (1997). *Intimate death: How the dying teach us how to live.* New York: Knopf.

Grey, A. (1994). The spiritual component of palliative care. *Palliative Medicine, 8*, 215-221.

Gunaratana, Venerable B.H. (1993). *Mindfulness in plain English.* Somerville, MA: Wisdom Publications.

His Holiness the Dalai Lama, Cutler, H.C. (1998). *The Art of Happiness: A Handbook for Liviing.* New York, Riverhead Books.

Levine, S. (1982). *Who dies? An investigation of conscious living and conscious dying.* New York: Doubleday.

Lo, B. (1995). Improving care near the end of life: Why is it so hard? *Journal of the American Medical Association, 274*, 1634-1636.

McCue, J. D. (1995). The naturalness of dying. *Journal of the American Medical Association, 273*, 1039-1043.

McKann, R.W., W.J. Hall, & Groth-Juncker, A. (1994). Comfort care for terminally ill patients: The appropriate use of nutrition and hydration. *Journal of the American Medical Association, 272*, 1263-66.

Memorial Society of Hawaii (2000). *What to do when death occurs.* Honolulu: Memorial Society of Hawaii.

Mermann, A. C. (1992). Spiritual aspects of death and dying. *Yale Journal of Biology and Medicine, 65,* 137-142.

Mitford, J. (1998). *The American way of death revisited.* Random House/Vintage.

Nuland, S.B. (1994). *How we die: Reflections on life's final chapter.* New York: Knopf.

Pietsch, J.H. & Lee, L. (1998). *The elder law handbook: Protecting your health, wealth, and personal wishes*. Honolulu: University of Hawaii Press.

Sharp, J. (1996). *Living our dying: A way to the sacred in everyday life*. New York: Hyperion.

Solomon, M.Z., L. O'Donnell, B. Jennings, V. Guilfoy, S.M. Wolf, K. Nolan, R. Jackson, D. Koch-Weser, & Donnelly, S. (1993). Decisions near the end of life: Professional views on life-sustaining treatments. *American Journal of Public Health, 83*, 14-23.

SUPPORT Principal Investigators. (1995). A controlled trial to improve care for seriously ill hospitalized patients: The study to understand prognoses and preferences for outcomes and risks of treatment (SUPPORT). *Journal of the American Medical Association, 274*, 1591-1598.

von Gunten, C.F., Ferris, F.D., Emanuel, L.L. (2000). Ensuring competnecy in end-of-life care: Communication and relational skills. *JAMA, 284,* 3051-3057.

Worden, J.W. (1991). *Grief counseling and grief therapy: A handbook for the mental health practitioner* (2nd ed.). New York: Springer.