



## End-of-Life Care: Diversity and Decisions Leader Guide

*“Every person is like all others, like some others, and like no others.”*

-adapted from quote by Clyde Kluckhohn, American anthropologist (1905-1960)

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### Introduction

Cultural diversity in the USA has implications for all aspects of life, including death-related experiences. We may be very familiar with the social norms of our own group, but how do other groups in our country approach death and dying, and the feelings and rituals involved? This lesson addresses differences in end-of-life support across cultures. It also includes information that might help to prepare for a "good death", including organ donations, the Advance Directive, Physician Orders for Life Sustaining Treatment (POLST), and hospice services.

### Lesson Objectives

After this lesson, participants will be able to:

- Describe some of the beliefs, practices or rituals regarding death, dying or grief, from cultural groups different from their own.
- Explain the differences between the use of the Advance Directive and the POLST.
- Name some of the services that hospice programs may provide.

### Materials Needed for the Lesson

- Sufficient member handouts and evaluation forms.
- Copy the six pages (attached) of beliefs and customs of other groups on to single-sided sheets
- Pens or pencils and sheets of plain paper
- (optional) Brochures from the local hospice organization in your county or area.
- (optional) sample advance directive and POLST forms

### Teaching Outline [Words in *italics* can be read to the group.]

1. Read the introduction and objectives for the lesson.
2. Ask each person to introduce herself/himself and say the name of a friend, relative, or acquaintance who died recently.

### **3. Setting the Stage: What is Diversity?**

*In this lesson, we will be discussing death, dying, and grief through the filter of diversity. Have a look at the aspects of diversity listed on the front of your participant handout. Take a private moment to think about how you would identify yourself in each of the aspects listed. Write your notes next to each diversity aspect. (wait 2 minutes) Let participants self-define the aspects.*

*Now, find a partner and share your self-identification descriptions with that person. **Important: Only share the information that you are comfortable sharing.** We'll hear a sampling among those of you who would like to share with the large group. (Do not call on specific people, rather say: Who would like to share their descriptions for one or two categories? Allow about 5 minutes for sharing)*

*Now have a look at the quote at the top of the first page of the participant guide. It says, "Every person is like all others, like some others, and like no others." When we are talking about diversity, it's important to remember that we are all human beings, and sometimes we may fall into specific groups that share beliefs and practices, but we are also unique individuals. As we go through the lesson today, let's be careful to avoid making assumptions about individuals based on group beliefs and practices. Even within our own group here today, there is great diversity. What may be true for some will not be true for everyone. Every human deserves respect.*

### **4. Exploring our own beliefs and customs regarding death and dying**

*Say: Let's divide ourselves into groups of 3 or 4 people. (give each group a pen or pencil and a sheet of paper) Let's explore what our own customs are around death and dying. Have a look at the questions in your participant guide. Please assign one person to be the recorder and use this paper to jot down the group's thoughts. You will have about 5 minutes.*

*Ask each small group to report on their findings to the large group. Allow two to three minutes per group. Verbally summarize the similarities and differences that are described.*

## 5. Exploring the beliefs and customs of other groups regarding death and dying

*As we begin this next activity, I want to remind us all that although we can identify specific beliefs and customs in another group, not all members of the group share every belief and practice. There is much diversity within groups, because each person is an individual, with his or her own unique interpretations of all aspects of life.*

Pull apart the sections at the back of this teaching guide that describe death and dying in various cultural groups. Distribute them to the small groups and ask them to read the descriptions and pick out key points to share with the large group. Allow 10 minutes for small group discussion, and about 5 minutes per small group for reporting back to the large group.

As each group finishes sharing their information, ask these questions of the large group (it is helpful to post these on a wall for all to see):

- *What surprised you?*
- *What would be the benefits of this cultural group's approach to death and dying? What would be the challenges?*
- *How does this new information change the way you think about this cultural group or about your own cultural group?*

## 6. Planning for a "good death"

Gather the large group back together.

*Let's switch the focus back to you and your wishes. Listen to this list of components of a "good death" and see if they resonate with you:*

- *Avoidance of suffering*
- *Being with family*
- *The touch of others*
- *Being mentally aware*
- *Not being a burden to others*

Allow a brief time for comments.

*Now let's do a brief review of tools that are related to preparing for terminal illness and death. Although very few people will use all of these tools, it's helpful to know that they exist.*

Review the information in the participant handout regarding organ donation, the Advance Directive, Physicians Orders for Life Sustaining Treatment (POLST), hospice services, and the Death with Dignity Act. **Suggestion:** divide the large group into small groups again, and ask each group's participants to study one topic and then share important points with the large group.

## 7. Closure

*These are some potential tools for advance planning for the end of life. There are also three conversations that need to take place to convey your wishes: 1) a conversation with yourself to determine what you really want, 2) a conversation with your health care provider, and 3) a conversation with family, friends, and advisors.*

*Please turn to the series of questions at the end of the participant guide. These are designed to open communication with relatives regarding end of life preferences. Allow a brief time for comments to wrap up the lesson.*

Distribute the informed consent statement and the program evaluation form. This evaluation is different from those used previously for FCE lessons. Please allow sufficient time and a quiet atmosphere so that the participants can read the statement and complete the evaluation with minimal distractions.

### References:

Advance Care Planning - Conversation Guide. Coalition for Compassionate Care of California  
<http://www.finalchoices.org/advance-health-planning.php>

A Memorial Quilt for Asian Grief and Loss: Implications for Grief Work and Counseling. Candy Vong, The University of Auckland (slide presentation)  
<http://www.fmhs.auckland.ac.nz/soph/centres/cahre/amh/AMH/grief.pdf>

Chinese Cultural Dimensions of Death, Dying, and Bereavement: Focus Group Findings. Alice G. Yick and Rashimi Gupta. *Journal of Cultural Diversity*, Summer 2002  
[http://findarticles.com/p/articles/mi\\_m0MJU/is\\_2\\_9/ai\\_93610991/](http://findarticles.com/p/articles/mi_m0MJU/is_2_9/ai_93610991/)

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Cultural Differences and Death (class notes), Kerr, Marcel S., Texas Wesleyan University Department of Psychology [http://faculty.txwes.edu/mskerr/files/3309\\_ch5.htm](http://faculty.txwes.edu/mskerr/files/3309_ch5.htm)

Customs and Values that May Affect Latino Grief. adapted from presentation by Yolanda Thompson. American congress of Obstetricians and Gynecologists.  
[www.acog.org/departments/dept\\_notice.cfm?recno=10&bulletin=799](http://www.acog.org/departments/dept_notice.cfm?recno=10&bulletin=799)

Donate Life Northwest (organ donation) [www.donatelifenw.org](http://www.donatelifenw.org)

Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. Jennifer S. Termel, M.D., Joseph A. Greer, PhD, et al. The New England Journal of Medicine, August 19, 2010 [www.nejm.org/doi/pdf/10.1056/NEJMoa1000678](http://www.nejm.org/doi/pdf/10.1056/NEJMoa1000678)

Living with Grief: Diversity and End-of-Life Care. Edited by Kenneth J. Doka and Amy S. Tucci. 2009 Hospice Foundation of America.

National Hospice and Palliative Care Organization [www.caringinfo.org](http://www.caringinfo.org)

Oregon Advance Directives [http://www.oregon.gov/DCBS/SHIBA/advanced\\_directives.shtml](http://www.oregon.gov/DCBS/SHIBA/advanced_directives.shtml)

Oregon Death with Dignity Act <http://www.oregon.gov/DHS/ph/pas/faqs.shtml>

Oregon Hospice Association. [www.oregonhospice.org](http://www.oregonhospice.org)

Oregon POLST Information <http://www.ohsu.edu/polst/programs/oregon-details.htm>

Physicians Orders for Life Sustaining Treatment Paradigm [www.polst.org](http://www.polst.org)

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## End-of-Life Care: Diversity and Decisions

### Blacks and African Americans

- Ethnic identity among blacks is as diverse as among whites, and can include descendants of slaves as well as immigrants from Jamaica, Haiti, Kenya, and other African countries.
- *Many blacks share a common fate of less robust health and wellness than whites. The scarcity of doctors in the black community contributes to a lower quality of life, less healthcare, and premature death.*
- Politically disadvantaged groups that have experienced long-standing discrimination and prejudice tend to mistrust medical systems identified with their oppressors. Also, the fear of medicine contributes to the tendency of many African Americans to avoid doctors and to seek care only at the last minute.
- *Many African Americans perceive death as part of the natural rhythm of life. They regard death, dying, and the dead with great reverence and respect.*
- Some oppose active euthanasia. Ground burial is often preferred.
- *They often invest greatly in funeral rituals and closely follow tradition and protocol, and they believe that attendance at and participation in funerals is an important social obligation. Non-attendance is perceived as being disrespectful.*
- Funerals tend to have longer planning stages, often occurring a week after the death, and the funeral does not start until all significant persons have gathered
- *Getting emotional at the funeral can be an expectation. Life after death, with the person transitioning to the spirit world, is a widely held belief.*
- It is common to engage in traditions to honor the dead, like naming a baby after the deceased person, passing babies over the caskets of loved ones, and acknowledging the presence of the dead at family gatherings.
- *One of the most highly valued expressions of condolence is the personal sacrifice of being present during the time of loss. It is the social norm among blacks to offer money, resources, and food to the survivors.*
- There are high expectations of clergy members to be active participants during illness, dying, and death.
- *African American women may struggle with two contradictory norms: to mourn the death openly and to project strength.*



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### American Indians and Native Americans

- The surviving American Indian people have very diverse tribal cultures. The U.S. government recognizes more than 550 tribes and many more are petitioning to be recognized.
- *For many American Indian, spirituality is at the core of their being. The ultimate good of human life has to do with relating to the sacred. Spirituality involves others. At the end of life the spiritual community is included in the dying process.*
- American Indians live for today, and the dying are still living. The focus is not on dying but on continuing the journey until death.
- *American Indian beliefs and traditions include reverence for every part of life, including death. The dirt, rocks, and trees are sacred. The ashes of the dead rest in sacred ground.*
- Rather than disconnecting, American Indians may continue to have a relationship with the dead. Some loved ones are perceived as still caring for and protecting those left behind.
- *For the dying, use of alternative medicines and healing ceremonies is common. Burning sage or the use of tobacco or sweet grass may be perceived as vital to healing for many groups.*
- Elders are respected and have the knowledge to help those who are dying and grieving. Grief is expressed immediately and there is a shared emotional release with mutual support.
- *When it's one's time to die, one should die naturally, without tubes or machines. American Indians are unlikely to use medically futile interventions, and they don't believe in showing love by trying to keep a person alive as long as possible.*
- It is important to not allow a loved one to die with strangers.
- *Often, the whole community will stop its day to day activity to participate in the funeral of a member of the tribe.*
- Non-verbal behavior and silence are valued, and generosity and sharing are dominant cultural values.

*Rituals vary. An example from a Southwest tribe: survivors have four days to cleanse and prepare body, bury it, mourn, and dispose of deceased's belongings. The body is washed and face is painted with a war paint made of soft red rock mixed with animal fat and corn meal. The person is dressed in their best clothes and the hair is tied with eagle feather to symbolize the return to home. After burial, the survivors cleanse selves of evil spirits and events of burial. Many tribes have also adopted Christian rituals as well.*



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### Latinos and Hispanics

- *There are many Hispanic and Latino subgroups, and there is also diversity in the levels of acculturation into mainstream culture.*
- *These subgroups for the most part share a common language, religion, traditional family structure, and several common Hispanic values.*
- *Emphasis is placed on the well-being of the family over that of the individual, so families are often included in end-of-life discussions with health care providers.*
- *The focus is often on the present rather than the past or the future. Mexican-Americans can be less likely to believe that a patient should be told about a terminal diagnosis. Mexican elders often want family members to make decisions about life support for them.*
- *Hispanics are more likely to want their doctors to keep them alive regardless of how sick they are. Hispanics are less likely to agree to stop life-prolonging treatment. They are less likely to talk about a pending death.*
- *Many Latinos hold the value that fate determines life outcomes, including health, and that fate is basically predestined.*
- *A belief in good and evil spirits that can affect health and well-being is common. Patients may seek spiritual healers such as **curanderos** instead of, or in addition to, standard medical treatment.*
- *Typically, Latinos express their loss by crying openly. Crying is viewed as a healthy and appropriate emotional response. Family and friends will often encourage survivors to outwardly express their grief.*
- *Another less common expression of grief and loss among some Latino cultures is **ataque de nervios** --general shaking that is believed to help release the pain of loss.*
- *Most often the church, family and friends contribute towards the burial and funeral expenses, especially if the body needs to be transported to the native land for burial.*
- *Family and friends may offer prayers for the deceased at various times. A novena (prayers for nine consecutive days) may be done, or prayers may be said once a month and then once a year. Special prayers and religious services are held on All Saints Day (November 1) and All Souls Day (November 2). Traditionally, these are days for visiting cemeteries. Relatives and friends bring wreaths of flowers, crosses, and other floral arrangements to decorate the graves of the dead in remembrance. Lighting candles and blessing the dead and their resting places also are important to many Latinos.*



## End-of-Life Care: Diversity and Decisions

### Asians and Pacific Islanders

- Asians and Pacific Islanders make up the third largest minority group in America. Their religious influences are mainly from Confucianism, Buddhism, and Taoism.
- *For many Asians, a "good death" is when a person dies at a ripe old age, with their eyes closed, at home in the native land, surrounded by family (especially sons and grandsons), and having fulfilled their last wishes.*
- A "bad death" may be one that is untimely, sudden, traumatic or one that happens in a foreign place. It may bring bad luck and shame and might be seen as a result of that person's or a family member's misdeeds in a past life.
- *Many Asian Americans were raised in cultures that taught that grief, like other emotions, should be kept to oneself or to one's family in order to "save face." On the other hand, some group customs may require openly showing grief, and even wailing at times.*
- Communication with health care providers about impending death may be restrained because of a belief that talking about bad things can make them happen. Death is often seen as bringing bad luck.
- *Death is a taboo subject among many Chinese Americans; many prefer for the dying individual to not be told that she or he is dying.*
- It is common for the father or oldest male to make decisions regarding treatment, care of the dying person and the funeral arrangements. This family patriarch also sets the mood for family mourning.
- *Asians and Pacific Islanders have many different traditional funeral customs, depending upon the cultural and religious background of the family. Post-funeral rituals can last for up to three years.*
- Funeral rituals can be very important to help create healthy relations between the living and the dead. Many Asians believe in reincarnation, and the deceased may become a beneficial ancestor.
- *The death of an infant or child is deeply mourned. Family members may wear white clothing or headbands for a period of time.*
- Sadness and grief may be expressed as physical body complaints, since mental illness is often considered a disgrace to the family.
- *Buddhist belief uses death as an opportunity for improvement in the next life. To enter death in a positive state of mind and surrounded by monks and family helps the deceased to become reborn on a higher level.*



## End-of-Life Care: Diversity and Decisions

### Judaism

- There are many variations in Jewish beliefs and they are linked to subgroups that include Reform, Orthodox, and Hasidic Judaism.
- *Jewish families have faced and resisted death not only in the Holocaust, but in every generation throughout history. They value life under all circumstances and may hold on stubbornly to life in the face of impending death.*
- Orthodox rabbis often will mandate that in virtually all circumstances, terminally ill patients should receive food and fluids by whatever means necessary.
- *It is customary to never leave the deceased person. There is a watcher who stays with the body until burial. Practitioners of Orthodox Judaism traditionally clean and prepare the body of the deceased person before transport to the funeral home.*
- Immediately after death, there is a rush to do everything necessary to bury the person within 24 hours. According to the Torah, leaving the deceased unburied is shameful disrespect to the dead.
- *At the burial, the fabric of a shirt or sweater is ripped on the left side directly over the heart at the death of a parent; on the right side, farther from the heart, for the death of other relatives. This act must be performed while standing, the posture of acceptance of grief, and the ripping symbolizes an act of controlled agony over the loss.*
- As soon as the burial is over, the mourners turn away from the fresh grave, and the compassion that had been focused on the dying person is re-focused on the mourners and their needs.
- *Mourners are visited by consolers, who "sit shiva" (stay with the mourners for 7 days) at the house. Mirrors are covered with cloths to discourage grievers from switching their focus from the spiritual to the physical. The mourner sits on a low stool, while guests sit on regular chairs in a semicircle around him. The mourner can speak or be silent, and the visitors listen. There is no food provided at this gathering. People come and go quietly, and the mourner is never left alone for seven days. These days are designed to give the mourners an opportunity to formulate their lasting memories of the deceased person.*



## End-of-Life Care: Diversity and Decisions

### Islam and Muslims

- Islam considers itself to be one of the great monotheistic (one God) faiths. Islam believes in a long line of prophets including Adam, Noah, Abraham, Moses and Jesus. Muslims believe that the last of this line is Muhammad.
- *For practicing Muslims, religion is a comprehensive way of life. The Koran addresses not only personal faith and theology but also religious and cultural regulations for the individual and community.*
- The main religious duties of a Muslim are a declaration of faith, five daily ritualized prayers, fasting from sun up to sundown during the month of Ramadan, an annual alms tax, and a pilgrimage to Mecca once during a lifetime. Each of these duties depends on the person's ability to perform it. For example, Muslims suffering from illness are not expected to perform the ritual fast.
- *Islam gives people great autonomy in determining their course of action. Thus, Muslims generally believe it is not permitted to force a person to experience a treatment he or she does not want.*
- A sense of responsibility for family, neighbors, and community is highly valued in Islamic ethics and law. Assistance to the ill and needy is a legal and moral responsibility, not an act of charity. Many immigrant Muslims rely on their families for support and avoid institutionalized care.
- *When a Muslim is near death, the position of the body is of great importance. They believe it is important at that time for the person to face Mecca, lying on his or her right side.*
- Immediately after the death, the patient's mouth and eyes should be closed, and the body covered. The body is not cremated or embalmed. Muslims try to bury their dead before the next sunrise or sunset, if possible. The body undergoes a ritual washing, is wrapped in a shroud, and is taken to the front of the mosque. Funeral rites are brief.
- *Beliefs differ among Muslim groups regarding organ donation, autopsies, withdrawal of life support, and "do not resuscitate" orders.*
- Mourning is usually for 3 to 7 days. Bereaved family members might not see their suffering after the loss of a loved one as a negative experience to be avoided. Mourning can be an opportunity for family and friends to reflect on relationships and strengthen their spirituality.