

Cultural Influences on End-Of-Life Care

News that you or someone you love is terminally ill can be shocking, stunning, or completely overwhelming. It's common to understand the news with your head first, but it takes some time to understand it with your heart.

The prospect of death brings up many sensations and many feelings, including fear, anxiety, nausea, dizziness, anger, guilt, a sense of helplessness, or worry—and all those feelings are normal. There's no right or wrong way for you to think and feel at a time like this.

An important first step to acceptance is acknowledging the information and deciding to live the rest of your life on your terms, or to support your loved one in the best way possible as they live the rest of their life on their terms. This means living in the present moment for whatever time remains.

Dying is a profound and uniquely individual experience, although the need for comfort, peace, dignity, and the presence of loved ones at the end of life is universal. Still, unique aspects of *culture*—beliefs, mores, norms, standards, and guidelines—can play a significant role in how you handle the dying process.

Many factors influence a person's culture and, therefore, choices about end-of-life care: worldview, ethnicity, geography, language, values, social circumstances, religion/spirituality, and gender.

For example, your culture probably influences your choices about types of support at the end of life, such as whether or not to use resuscitation measures, medications, medical interventions, or feeding tubes or whether or not to withhold nutrition and fluids.

The prospect of death brings up many sensations and many feelings, including fear, anxiety, nausea, dizziness, anger, guilt, a sense of helplessness, or worry—and all those feelings are normal.

Your culture can influence who is with you or your loved one as they are dying, and whether you or your loved one will choose to die at home, in the hospital, or in a hospice facility. Culture can also influence the foods eaten and the clothes worn during the rituals and ceremonies that accompany and come after the dying process. Some cultures treat death with the utmost reverence while others prefer to celebrate the life before it. Other cultures fear death.

Communicating your cultural beliefs will help care providers more fully support you as a whole person. Making your beliefs and values known to those who are providing your care (or your loved one's care) helps ensure that these wishes are respected.

Content Provided By:

Sponsored By:



Since dying is a unique experience profoundly influenced by culture, you and each of your family members may cope with the dying process in a different way. Past losses, levels of education or experience, spiritual and religious beliefs, and personal philosophies may all affect feelings, reactions to, and expressions about dying. By embracing your cultural background, dying and death is more likely to be meaningful and peaceful.

Religious and Spiritual Beliefs

Dying is a profound process of transformation, and for many it's a spiritual and religious event. During this time, attention usually shifts away from the outer distractions in the world and turns inward toward a personal search for greater meaning, peace, and comfort, as well as spiritual fulfillment.

Religious and spiritual beliefs may play an important part in making sense of both life and death. As you search for meaning in your own or someone else's death, spiritual/religious issues may surface. During this experience, you may ponder deep existential issues.

Faith can help you view your life within the context of a greater purpose or a connection to something bigger than yourself. Spiritual beliefs and religious practices can also support you if you find that you are angry with God or your Higher Power, or if you find you are experiencing a crisis of faith. Finding meaning during death and dying is a personal journey. Seeking support, guidance, and compassion from family, friends, and spiritual or religious advisors can be especially helpful during this journey.

You may also find that certain rituals or practices are helpful as you seek ways in which your faith and spiritual beliefs can support you during the last phases of life. These may include:

1. Engaging in prayer or meditation.
2. Including loved ones in the provision of care and rituals for the dying person. Be grateful for, and accept help from, different sources.
3. Accepting that some family members and friends will treat you differently than they may have in the past. Try to move past their discomfort and treat them as you have always treated them.
4. Allowing time to share feelings and thoughts. Don't be afraid to ask to be alone.
5. Accepting gifts from family and friends graciously because it will make them feel better.
6. Forgiving yourself and others and recognizing that you are responsible for the emotional issues you are holding onto as you or your loved one makes this journey.
7. Completing any unfinished business you might have with family, friends, or loved ones.
8. Remembering that no one can completely understand what you need or want or what you are experiencing. Try to communicate your feelings and your needs effectively so others can provide you with support, compassion, and love.

Involve Your Senses

Every culture since the beginning of time has used rituals and ceremonies to address death and dying. These rituals and ceremonies are powerful reminders of the fragility of life, they help remind us of possibilities after we die, they provide a sense of peace and comfort, and they create spiritual connections to those who have passed before. When creating rituals and ceremonial acts to support the dying process, remember to incorporate the senses of touch, smell, taste, sight, and hearing. Doing this helps you feel grounded, whole, and connected to your self.

- **Touch:** Touching is a powerful way to break the isolation, loneliness, and fear of dying. In most cases, touching other people or favorite animals can bring a sense of peace and calm.
- **Smell:** The sense of smell can elicit powerful emotions at any stage of life. The dying process may change the types of fragrances that can be tolerated, but mild-smelling odors are usually acceptable. Natural scents like lavender, rosemary, or vanilla are usually tolerated the best.
- **Taste:** The sense of taste varies for each individual and usually remains intact until the end of life. If you or your loved one can no longer eat, this can be a normal aspect of the dying process and the sense of taste can be supported by possibly

allowing you or your loved one to suck on a favorite hard candy or a soft oral sponge soaked in something appealing.

- **Sight:** Arrange objects that have meaning to you within easy view. These objects should symbolize positive people, places, and events in your life. A room lit by soft, subdued sunlight can also provide a sense of serenity.
- **Hearing:** The sense of hearing is often sharp even to the end of life, so special words at death can be heard and provide a sense of meaning to those who speak them and to those who hear them.

Healing Activities

Cultural beliefs and practices strongly influence end-of-life views and the care that needs to be provided during this time. Your requests for culturally specific end-of-life rituals and ceremonies such as funeral, burial, and mourning practices are important and should be conveyed to those who love you as well as to your caregivers.

During the dying process, you may need time to be by yourself. Some family members and friends may feel driven to fill your every waking moment with activities or conversation. Perhaps they are trying to take your mind off the impending death, but they may also be anxious, frightened, or uncomfortable with the sights, sounds, thoughts, and feelings that surround dying and death. Remember, while these individuals may be very important to you, your needs are the priority.

It is important to spend your final months, weeks, or days of your life, or your loved one's life, in a way that best suits you and your family and friends. You may want to spend time talking or simply being together with those who mean the most to you.

You might find some of the following activities healing and supportive to you as you or your loved one prepares for death.

- **Journal Writing:** Journal writing can be a comforting healing technique that allows you to process your innermost thoughts and feelings in a safe, private way. Journaling can be done as a family or individually. Recollections, family stories, and thoughts about time spent together can be written down. Adding pressed flowers, photos,

small mementos, and other items to a special book will help memorialize your life.

- **Family Photos:** You and your family members may want to select photos to put in a special album and write captions next to each photo. Younger family members may enjoy recapturing memories and appreciate learning about their family's history.
- **Music:** Music is a therapeutic way to support your physical, mental, and spiritual/religious healing. Music is especially useful when communication between family, friends, or loved ones occur as a result of the stress and emotions surrounding the dying process. Gentle environmental sounds like ocean waves, wind, rain, birds, and music from harps, flutes, or stringed instruments may provide a sense of peace. Use music that helps you feel a sense of relaxation, calmness, and serenity.
- **Life Assessment:** A life assessment involves asking yourself questions, such as "What do I need to do, or let go of, in order to be more peaceful?" "What am I grateful for?" "What have I learned about courage, strength, power, and faith?" "How am I handling this suffering?" "What will give me strength as I die?" By answering these types of questions, you may discover many insights that help you handle the journey of dying.

Culture and Pain Management

A key component of palliative and hospice care is the effective and compassionate treatment of your pain. Nurses, physicians, psychologists, social workers, pharmacists, spiritual advisors, alternative and complementary therapists, and other allied health professionals are among the individuals who may assist you in managing your pain.

Your care providers will assess and help relieve physical suffering, as well as psychological, social, and spiritual/religious distress. It is important to communicate your beliefs and values about pain if they may affect your response to pain, treatment options, and whether you wish to use traditional healing practices versus Western medical treatments.

Many alternative or complementary practices are used in various cultures. Several are listed below. If you will be using them for pain management or other

therapeutic reasons, it is important to inform your care provider.

- Herbal remedies
- Therapeutic touch
- Acupuncture
- Acupressure
- Application of heat or cold

You alone are the authority regarding the presence of your pain, and you have a right to communicate what works for you and what is not effective in the management of your pain.

Communicating Your Cultural Needs

End-of-life is a vulnerable time for you and for those you love. The more effectively you communicate your unique needs, values, and rituals related to death and grief, the more compassionate and caring those who care for you can be. A lack of communication with your healthcare providers can lead to misunderstanding and insensitivity, as well as misinterpretation of symptoms, diagnoses, and interventions. You are a unique individual and your cultural beliefs and values deserve respect.

Effective communication facilitates planning and intervention strategies that can be used to support the care you want to receive during this time in your life. Learn about your specific illness or condition so you are better able to understand what is happening to you and feel some sense of control over this process. Express your feelings, provide your caregivers with information about your specific needs, and be as open as you are capable of to living in this moment.

The following questions may be difficult to discuss but are important to consider when having a conversation about culturally respectful care at the end of life. Discuss them among family and loved ones.

- Have you appointed someone to be in charge of your medical decisions?
- How do you wish to be cared for during the process of dying?
- Have you planned rituals for your burial, funeral, memorial service, or cremation?

- Have you planned what prayers, passages, poem, or music you want used in your memorial or funeral?

Dying is a journey that you take alone. However, during this journey, remember that family, friends, and your faith can offer immense comfort to you in times of distress. While it may be difficult, remain open and loving to people who love you and want to support you during this time.

References

- Corr, C. & Corr, D. (2012). *Death & dying, life & living*. Belmont, CA: Wadsworth/Cengage Learning.
- Doka, K.Y. (2011). Understanding the spiritual needs of the dying. Retrieved March 15, 2011 from http://www.huffingtonpost.com/kenneth-j-doka/spiritual-needs-of-the-dy_b_831123.html
- Dossey, B. M. & Keegan, L. (2013). *Holistic nursing: A handbook for practice* (6th ed.). Sudbury, MA: Jones and Bartlett Publishers.
- Lueckenotte, A. G. & Meiner, S. (2011). *Gerontologic nursing* (4th ed.). St. Louis: Mosby Elsevier.
- Mayo Clinic. (2011). Terminal illness: Supporting a terminally ill loved one. Retrieved March 31, 2011 from <http://www.mayoclinic.com/health/grief/CA00041>
- Palmer, A. (2008). Coping with death and dying. Retrieved March 30, 2011 from <http://www.asrn.org/journal-nursing-today/325-coping-with-death-and-dying.html>