



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

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

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

<b>Aspects of the Complex Nature of Cultural Diversity and Identification</b> (use your own definition of each)	<b>How do I describe myself?</b>
Race	
Ethnicity	
Gender	
Culture	
Age	
Class or Status	
Geographic Roots	
Spirituality and religious beliefs, or non-beliefs	
Sexual orientation	
Disability	
Socio-economic background	

### Exploring Our Own Beliefs and Customs

#### Before Death:

- *In your cultural group, are certain types of death less acceptable than others? Are certain types of death especially harder to handle?*
- *What are your group's beliefs about what happens after death?*
- *Is the person with a terminal illness told about their own imminent death?*
- *Where does the dying person reside before death?*
- *Who cares for the dying person? Who visits?*
- *What are the expectations for how the dying person should behave or act?*
- *What are the expectations for how the friends and relatives of that person behave or act?*

## **After Death:**

- *What happens to the body immediately after death? Is the body cremated? Embalmed? Buried? Who cares for the body?*
- *Do specific family members have defined roles in handling the death?*
- *Describe your community's rituals surrounding a person's death. How soon do they happen after death? Where do they happen?*
- *Describe how the mourners are assisted (or not assisted) as they cope with their grief. What are acceptable expressions of grief in your cultural group?*

## **Some possible tools that may help plan a "Good Death"**

### **Organ Donation**

Are you interested in helping others in a meaningful way at the time of your death? All major religions practiced in the U.S. support organ donation as a charitable act. Here in the Pacific Northwest, donations are coordinated by Donate Life Northwest ([www.donatelifenw.org](http://www.donatelifenw.org)). Their website answers frequently asked questions about organ donation. In Oregon there are three ways to join the Donor Registry. You can put a "D" on your driver's license, permit or ID card (details are at local DMV offices), you can register online at the website, or you can fill out a paper form (to request paper form call 1-800-452-1369). All three methods are equally meaningful. The license "D" designation allows donation of all organs and tissue. If you want to be more specific regarding the types of organs you want to donate, use the online or paper methods.

### **Advance Directive**

An advance directive is an optional set of instructions that explain the specific health care measures a person wants if he or she should have a terminal illness or injury and become incapable of indicating whether to continue curative and life-sustaining treatment, or to remove life support systems. The person must develop the advance directive while he or she is able to clearly and definitively express him or herself verbally, in writing, or in sign language. It must express the person's own free will regarding their health care, not the will of anyone else. It does not affect routine care for cleanliness and comfort, which must be given whether or not there is an advance directive. There are specific instructions for witnessing of the document. Download a copy of the Oregon form at: [http://www.oregon.gov/DCBS/SHIBA/docs/advance\\_directive\\_form.pdf?ga=t](http://www.oregon.gov/DCBS/SHIBA/docs/advance_directive_form.pdf?ga=t)  
If an advance directive is completed, it should be shared with medical providers, the person you designate as your health care representative, and family members. Emergency medical personnel may not know about an

advance directive that has been written, and are required to perform emergency assistance if called to assist.

**Physicians Orders for Life Sustaining Treatment (POLST)**

Physician Orders for Life-Sustaining Treatment (POLST) is a program that uses a bright pink medical order form about your goals of care and end-of-life treatment wishes. It can be used when you have a serious illness that is in the advanced stages and is not curable. The form is completed by your physician, nurse practitioner or physician assistant. The POLST form helps you be cared for the way you want and according to your wishes. It makes clear what medical care you would or wouldn't want if you become unable to make the decisions yourself. Because it is a medical order, it also requires health care workers (like paramedics and others) to follow your plan. A POLST brochure is available at: <http://www.ohsu.edu/polst/resources/documents/Brochure2009.pdf>. To see a sample of the Oregon POLST form, go to this website: <http://www.ohsu.edu/polst/programs/documents/POLST.JUNE.2009sample.pdf> For general POLST information go to: [www.polst.org](http://www.polst.org) .

**How Advance Directives and Physician Orders for Life-Sustaining Treatment (POLST) Compare**

	ADVANCE DIRECTIVE	POLST
For whom:	For anyone 18 and older	For persons with advanced illness -- at any age
Purpose:	<ul style="list-style-type: none"> <li>• Instructions for <b>future</b> treatments</li> <li>• To appoint a Health Care Representative</li> </ul>	Medical orders for <b>current</b> treatment
Guide actions by Emergency Medical Personnel when made available:	<b>NO</b> (with rare exception)	<b>YES</b>
Guide inpatient treatment decisions when made available:	Yes	Yes

Developed by Oregon Health Decisions and the Oregon POLST Task Force, 2010

## **Hospice Services**

Hospice is a philosophy of compassionate and comprehensive care for dying persons and their families that addresses the medical, psychosocial, spiritual and practical needs of the individual and the related needs of the family and loved ones throughout the periods of illness and bereavement. Hospice is palliative or comfort care, a good choice when curative treatment is no longer effective or no longer wanted and when life expectancy is measured in months or weeks. Palliative care focuses on comfort, but prolonging life may be part of the goal. It's provided by hospice and palliative care teams of doctors, nurses, social workers, and other counselors. Recent research has shown that patients who received earlier palliative care while undergoing medical treatment had better quality of life and survived longer than those who did not.

Hospice makes it possible for people to choose to remain at home, or in a homelike setting. While home is the most common and the preferred place for many patients, it is not always possible or even desirable for all hospice patients. Individual patient, family and caregiver needs determine the location for delivery of hospice care. Patients can receive the services of the hospice team at home, in a hospital, in a nursing facility or inpatient hospice, in a residential hospice, or in a long-term care or other residential facility.

Services may include:

- Intermittent home and hospital visits by nurses and other health care professionals
- Management of pain and symptom control
- Medical treatments as prescribed
- Instruction and supervision of family members in patient care
- Personal care and household services
- Providing or arranging for respite or continuous care
- Assistance in obtaining medical equipment, supplies or medications
- Physical, occupational and speech therapy
- Short-term inpatient care for respite or symptom management
- Counseling and emotional support for patient and family
- Spiritual support
- Companionship and practical services by lay volunteers
- Information and guidelines regarding insurance, financial aid, in-home support and transportation agencies, community agencies
- 24 hour, 7 day a week on-call emergency/crisis assistance
- Music therapy
- Pet therapy (Assisted Animal Therapy)
- Massage therapy

Hospice care is covered by Medicare, the Oregon Health Plan and private insurance. Through Medicare and most insurance plans, the hospice program manages the total care and costs of treating the terminal illness. Medical services, outpatient drugs and biologicals, counseling and bereavement, room and board, and attending physician or Nurse Practitioner services are paid for by the hospice provider. Patients may be asked to meet co-pay or other uncovered costs. However, no one will ever be turned down for financial reasons. There are more than 70 hospice programs in all areas of Oregon. For more information and a directory of hospices, go to [www.oregonhospice.org](http://www.oregonhospice.org) . The National Hospice and Palliative Care Organization has a helpful website for all aspects of end-of-life care at [www.caringinfo.org](http://www.caringinfo.org) .

### **Death with Dignity Act**

On October 27, 1997 Oregon enacted the Death with Dignity Act which allows terminally-ill Oregonians to end their lives through the voluntary self-administration of lethal medications, expressly prescribed by a physician for that purpose. The law states that, in order to participate, a patient must be 18 years of age or older, a resident of Oregon, capable of making and communicating health care decisions for him/herself, and diagnosed with a terminal illness that will lead to death within six months. It is up to the attending physician to determine whether these criteria have been met. For more information go to <http://www.oregon.gov/DHS/ph/pas/faqs.shtml> This law is controversial and information is provided in this lesson only to create awareness.

### **What now?**

**There are three conversations to have:** First, with yourself (what are my preferences and wishes?), second, with your health care provider, and third, with your family, friends, and advisors.

### **Questions to ponder -- share your answers with family members and friends.**

- If you could plan it today, what would the last day or week of your life look like?
- Who would be there? Where would you like to be?
- What are your ideas and hopes about the end of your life?
- What are your fears or concerns about the process of dying?
- Have you thought about the care you want during a severe illness or as you are dying?
- Where would you prefer to spend your last days if you are ill? At home, at a family member's home, in a hospice, or in the hospital?

- Who do you want to make medical decisions for you if you are unable to speak for yourself?
- Do you believe that life should always be preserved as long as possible? If not, what kinds of mental or physical conditions would make you think that life-prolonging treatment should no longer be used? For example, if you were:
  - Unaware of your surroundings
  - Unable to appreciate or continue important relationships
  - Unable to think well enough to make everyday decisions
  - In severe pain or discomfort
- Is there any particular music, flowers, photographs or art you would like to have around you at the end?
- What are your wishes regarding a funeral? Burial vs. cremation?

(from California Coalition for Compassionate Care. [www.finalchoices.org](http://www.finalchoices.org))

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