

End-of-Life Care

A Successful Rx for Oregon

by Anne Jackson and
Barbara Roberts

Today, Oregon's status as a national leader in end-of-life care is recognized beyond its borders. The Death With Dignity Act is just one innovation in a long list of laws granting rights to Oregonians at the end of life. The state has avoided the public health crisis predicted by Death with Dignity Act opponents by providing a comprehensive end-of-life care infrastructure that promotes comfort for the terminally ill, values advance planning, and allows more Oregonians to die at home.

Oregonians who ended their lives under the Act did so for reasons of autonomy and control. They were not disproportionately poor, uneducated, or uninsured. They were not denied access to hospice and comfort care, denied pain control, or burdened by financial fears. Oregon's death rate has not climbed as a result of people moving here to die. Many considered all of the above outcomes inevitable if physician-assisted suicide became legal in our state. Perhaps the numbers were lower than predicted because state law provides terminal patients with other legal rights that address most of the reasons Americans give for favoring legalized physician-assisted suicide, including fear of pain. Because most Americans don't want to talk about death or dying, however, many of us remain unaware of these options.

Dying Oregonians have a legal right to pain relief.

Under the Health Care Decisions Act terminally ill Oregonians shall have "comfort

measures." Comfort measures include medication to relieve pain and other distressing symptoms, even if death is hastened as a result. Oregon's prescribing laws are the least restrictive in the United States. Our morphine consumption rate, a crude indicator of physicians' willingness to prescribe strong medications, is consistently among the nation's highest. The Oregon State Board of Medical Examiners (OBME) routinely issues statements encouraging doctors to treat pain appropriately. In 1999, the OBME was the first in the nation to sanction a physician for inadequate pain management.

Oregonians have a right to refuse or to stop treatment.

Being hooked up to machines or given medications to delay death are two more reasons people give for favoring legalized physician-assisted suicide. Oregonians can refuse treatment when it is offered or stop treatment once it's started. Provisions to refuse treatment for individuals with incapacitating illnesses such as advanced Alzheimer's disease can be made in advance directives, instructions for medical treatment written while the individual is still able to make healthcare decisions.

Many Americans, including healthcare professionals, are conditioned to believe that denying food and water, even when it isn't wanted, is tantamount to starving or abandoning the patient. Oregonians have the legal right to refuse to eat or drink. Most will stop eating and drinking because they are no longer hungry as death nears, but a few will do so in a deliberate effort to hasten death.

The reality is that nutrition and hydration at the very end of

life can cause great discomfort. No research supports the concept that feeding tubes prolong life or add to its quality. The same holds true for CPR when an individual is frail or elderly.

Extraordinary measures can also be refused. Pneumonia, formerly the “old person’s friend,” is routinely treated with antibiotics while that same “old person” may be going to bed every night pray-

ing that he/she won’t wake up. Antibiotics for pneumonia or other infections and ventilators to assist breathing can be refused or discontinued by request or through an advance directive.

Oregonian’s have a right to make advance directives.

All Americans should discuss preferences about the end of life with their families and their doctors. They should complete advance directives stating their wishes and appointing surrogates to make decisions on their behalf when they are unable to do so. Without an advance directive the presumption is made that an individual wants full treatment, even if that treatment may be futile.

Not only can an advance directive protect the patient, an advance directive can also protect loved ones. In one of the first studies to actually measure the impact, a 2001 OHSU study confirmed that family members who make decisions to stop life-sustaining treatment experience extraordinarily high levels of stress. The study revealed that stress was highest in the absence of advance directives, at twice the level experienced by families who lost their homes in Oakland wildfires in the early 1990s. “Survivor guilt” is a very real phenomenon, even when death is inevitable. Family members often

relieve the death of their loved ones, concerned that they should have done something differently. The knowledge that their actions were consistent with what their husband or mother wanted—as addressed in an advance directive or in conversations about their wishes—can, in fact, be comforting. Preferences for hospice and comfort measures can be indicated in advance directives, if a person becomes terminally ill. A lawyer is not needed to complete these documents.

Another option available to Oregonians is the Physician Orders for Life-Sustaining Treatment (POLST). This converts a patient’s wishes expressed in an advance directive into written doctor orders. Unlike an advance directive, which is appropriate for all adults, the POLST is recommended when a life-threat-

Emergency personnel have been authorized by the OBME to respect the POLST.

A 1997 Oregon Health and Science University study revealed that 68% of adult Oregonians who died that year had completed advance directives, compared to an estimated 20% nationally. The national SUPPORT study (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments), carried out in the late 1980s and early 1990s, revealed no correlation between what someone said they wanted and what they got. That is not true in Oregon. The 1997 OHSU study indicated that family caregivers believed their loved ones’ wishes were respected 85% of the time. When the POLST was completed by their healthcare practitioners, respect for wishes was 98%. Oregon’s POLST pro-

OHP and Hospice

The goal of the Oregon Health Plan, when it was passed in 1987, was to ensure basic healthcare including “Comfort Care and Hospice,” for all Oregonians. Because federal waivers requesting special use of Medicaid dollars and mandated employer-participation were denied, the plan was never fully implemented. Although hospices provide care without regard to a patient’s ability to pay, the right to hospice and comfort care granted in 1987 is elusive. Bills to provide hospice for the few dying Oregonians who fall through the cracks have since been introduced to the legislature three times. None has made it to the floor, although hospice is both more cost effective and humane than the public and personal costs of the medical crises that occur when an individual has no support.

Many mistake hospice for a kind of nursing home, but hospice is provided at the patient’s “home,” wherever the individual lives.

ening event can be anticipated. A completed POLST form can assure, for instance, that hospice patients and nursing home residents are not inadvertently harmed by life-saving measures that can break frail bones. Unlike a DNR (do not resuscitate order), the POLST, a watermelon-colored form, allows an individual to choose what they do or do not want at the end of life.

gram has won much national and international attention. A Japanese version was recently distributed to the POLST task force.

Hospice and comfort care.

All Oregonians, not only those who are dying, should know about hospice and comfort or palliative care. Hospice addresses the medical, psychosocial, spiritual, and practical needs of the individ-

ual and the family. Hospice, under most health plans, covers everything related to the terminal illness, including medications, supplies, and equipment. Hospice is intermittent care available 24 hours a day, seven days a week. Hospice effectively addresses the fears people give for politically favoring or personally considering physician-assisted suicide: the fears of pain or suffering, of being alone, of being a burden, or of losing control. Hospice effectively addresses the symptoms that cause suffering. Nearly 80% of individuals who ended their lives between 1998 and 2001 under the Oregon Death With Dignity Act were hospice patients. Researchers in a recent New

predicted outcomes, researchers found that hospice caregivers ranked depression, lack of family support, and being a financial drain as unimportant factors in the decision for a request.

Hospice is an excellent choice when curative treatment is no longer effective or becomes burdensome. A patient and his/her family do not have to agree that he/she is "dying," but they do have to understand that the nature of hospice care is comfort, not cure. Hospice is a win-win situation: if patients get better, they'll no longer be eligible; if they change their mind, they can return to curative or life-prolonging treatment. Comfort or palliative care is a healthcare

discipline that has evolved to address the pain and symptoms of those individuals facing a life-threatening illness who may not want or who are not yet eligible for hospice.

Patients and families should consider hospice earlier, rather than later, to benefit fully from the support and services it provides. Individuals are eligible for hospice when they have a life expectancy of six months or less, but hospice care

is usually unlimited. Half of all hospice patients in Oregon die within 17 days of admission, an indication that many are referred too late. A 2000 Oregon Hospice Association (OHA) study revealed

that individuals who died in hospice care in fewer than 14 days were more likely to have experienced an unnecessary crisis resulting in a 911 call and a hospital admission prior to their hospice referral. Later referrals are costly, as well as inhumane. The costs of just one day in a hospital can equal the costs of 15 days of hospice care in a patient's home.

Nine out of ten Americans facing the end stages of a life-threatening illness would prefer to die at home. Eight out of ten Americans would want the services hospice offers, but a significant number of those polled did not associate the word hospice with the list of services offered. Many mistake hospice for a kind of nursing home, but hospice is provided at the patient's "home," wherever the individual lives. A hospice patient may live in his/her own or a relative's home, a nursing or foster home, residential care or assisted living facility, or a residential hospice. Hospice provides its care across all settings, including inpatient and respite care in a hospital or inpatient hospice.

Dying Oregonians do not have to choose between hospice and physician-assisted suicide. They can choose

The Current State of Assisted Suicide

In Oregon, according to polls conducted before and after the elections, many people's fear of pain motivated them to vote for physician-assisted suicide. The truth, however, is that uncontrolled pain has been an insignificant factor for those individuals who actually have ended their lives under the Death with Dignity Act. Between October 1997, when the injunction blocking implementation of the Death with Dignity Act was lifted, and December 2001, 91 terminally ill Oregonians ended their lives by ingesting lethal medication. Not thousands, as predicted during public debates in 1994 and 1997, when voters twice approved the law, but 91—a rate of less than 1/10th of one percent of all deaths. The Department of Veterans Affairs, Oregon Health Sciences University, Oregon State University, Portland State University, the Oregon Hospice Association (OHA), and other institutions are conducting independent and unbiased research projects to add more information critical in evaluating the impact of the law and developing future public policy.

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England Journal of Medicine study concluded that the high quality of end-of-life care provided by Oregon's hospices may help explain the very low rate of physician-assisted suicide. Contrary to

both. No Oregon hospice will turn away a patient who intends to use the Death With Dignity Act. No Oregon hospice wants someone to use physician-assisted suicide for a reason that hospice care can fix. No Oregon hospice wants someone to choose physician-assisted suicide because they haven't an affordable alternative.

So, is Oregon the best place to die?

The numbers indicate Oregon's success at providing its citizens with what they want at the end of life. Oregon's death rates at home and in nursing homes are the highest in the nation at approximately 35%. Portland's death rate in the hospital was 22% in 1994-95 and remains the lowest in the nation. The low rate of hospitalization in Oregon means that care is much less expensive. Medicare spending during the last six months of life was \$3,900 per capita in Portland, compared to \$7,850 in Miami; the level of patient satisfaction was the same in both locations.

Facts and figures measured against wishes and preferences provide compelling support to claims that Oregon may be the best state in which to die—and clear evidence that it can be better. Oregon's first hospice, developed in 1977, was among the first in the nation. The first palliative care teams in the nation were established in Oregon in the late 1980s and early 1990s. The most remote and rural counties offer hospice services to residents. Harney County—10,000 square miles, 7,600 people and defying conventional wisdom—has had hospice since 1992. Oregon's hospice penetration rate (hospice deaths/total deaths) is among the highest in the nation, at 40% in 2001. However, Arizona's rate

is the highest at more than 50%. Arizona's rate is a good target and Deschutes County already exceeds that number.

Facts and figures provide little comfort when one's own mother, one's beloved, or one's self is facing the end of life. Dying isn't easy, and the best infrastructure in the world isn't going to make it so. Nevertheless, it is helpful to know that the course through every life-threatening illness involves hard choices and a critical need for clarity and communication among the patient, loved ones, and the medical community. The number one complaint about hospice care is and has always been, "why didn't we know about hospice earlier".



Anne Jackson is executive director and chief executive officer of the Oregon Hospice Association (OHA). Jackson is active on the Task Force to Improve Care for Terminally Ill Oregonians, the Physicians Orders for Life Sustaining Treatment Task Force (POLST), and the Health Ethics Network of Oregon (HENNO). She is a member of the board of Combined Health Charities in Oregon. Nationally, Jackson is a member of the National Hospice and Palliative Care Organization's (NHPCO) Council of States steering committee and the State Hospice Executives Roundtable (SHOER). She worked with Senator Ron Wyden's office to develop legislation for a demonstration project expanding the Medicare Hospice Benefit and is a member of Congresswoman Darlene Hooley's advisory committee on healthcare.



Barbara Roberts currently serves on the boards of trustees for the Oregon Hospice Association, the Women of the West Museum in Boulder, Colorado, and the Human Rights Campaign in Washington, D.C. She also is a member of the Advisory Councils for Compassion in Dying of Oregon, and the Oregon League of Conservation Voters. She is also involved in a new Relief Nursery in Portland, serving small children who are victims or at-risk of abuse or neglect. Barbara Roberts is an active public speaker, now focusing on issues of death and grieving, women in politics, leadership, and environmental stewardship. Governor Barbara Roberts signed the Health Care Decisions Act into law in October 1993, while her husband, Senator Frank Roberts, was dying with the support of hospice.