

Making choices about dying and death

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A new book tells the stories of some people who have carried out doctor-assisted suicide

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Ten years ago, 11 Seattle AIDS activists and caregivers founded a group called Compassion in Dying. Their goal: Expand the choices available to dying patients, including the option of hastening death by taking a lethal overdose.

Compassion in Dying is now based in Portland, in the only state where assisted suicide is legal. Oregon's 6-year-old Death With Dignity Act allows doctors to prescribe a lethal dose of barbiturates to a terminally ill adult of sound mind who requests it in writing.

"We've made it acceptable," says Barbara Coombs Lee, 56, president of the Compassion in Dying Federation. "There's now a pretty large consensus -- certainly not everyone agrees, but many do -- that it's possible and ethical to give people a choice of assisted dying during their terminal care."

The Oregon law is being challenged in court by the Bush administration, which claims it violates federal drug laws. A three-judge panel of the 9th U.S. Circuit Court of Appeals heard arguments in May and could rule at any time.

Trained as a nurse and a lawyer, Lee has edited a new book, "Compassion in Dying: Stories of Dignity and Choice" (NewSage Press, \$12, 138 pages). Lee was interviewed in her Northwest Portland office. Her comments were edited for length and clarity.

Q. Who do you imagine reading this book?

Making choices about dying and death

A. Anyone curious about what they're doing about dying "out there in Oregon." There's a notion that it's a peculiar law for those peculiar Oregonians. But what the stories indicate is that these people are just like families all across the country.

Q. Have you been surprised by the relatively small number of Oregonians -- about 30 a year -- who have carried out a doctor-assisted suicide?

A. A lot of people are surprised. But because Compassion in Dying had four years of experience (before the Oregon law), we knew that many people made an initial inquiry and never followed through.

Q. Dying is a pretty private thing. Is there a danger that some readers will feel like they're gawking?

A. Oregon has so much to teach the rest of the nation. For these individuals who wanted to be public about it, it's part of the legacy they want to leave.

Q. Isn't one of the arguments (against assisted suicide) that virtually all pain is manageable -- so why is any of this necessary?

A. It's not about pain, though. I think most people understand in 2003 that their pain can always be controlled if they're willing to bargain away consciousness for pain relief. I hope this book helps Oregon bring to the nation the understanding that choice prolongs life because it restores hope and it increases endurance: I can tolerate this if I know I don't have to.

Q. You helped draft Oregon's Death With Dignity Act. If you were to redraft it, what would you change?

A. I wouldn't change a word.

Q. Why does Oregon remain the only state with such a law?

A. The easy answer is the power of politics. But the hopeful answer is that Oregon really was the pathfinder -- the state that would establish the truth about what adding choice does to end-of-life care. It improves care. It improves the rate at which hospice is utilized. It improves the effectiveness

Making choices about dying and death

with which pain is treated. It heightens physicians' awareness about depression and other treatable mood changes at the end of life.

Q. What is it about Oregon that made it the first state to legalize doctor-assisted suicide?

A. I think of Oregon as a can-do state. We're self-confident: This is doable, this makes sense. Bottles should be redeemable. Beaches should be accessible. It's not, you know, such a scary thing. We think we do right by our people, by giving them choices.

Q. What is the biggest public misunderstanding about assisted suicide?

A. The greatest misconception is that good end-of-life care and the choice of assisted dying are an either-or proposition. Our perspective is that you improve end-of-life care as much as you possibly can, but until you add empowerment of choice at the end of life, you will never be (fully) successful.

Q. One of the stories in the book is that of Roger Watanabe, who told family and friends just before he swallowed a lethal overdose: "If I can help people accept their aging process, and the process of their own dying, as natural, then I will be happy." But if death is so natural, why subvert it by something as unnatural as suicide?

A. I think our experience in Oregon and our movement for choice at the end of life are all part of a much greater movement -- of reclaiming death as a natural part of human experience. It is a rebellion against the denial of death, the overemphasis on technology of death, the placement of death in temples of technology, with machines and curtains drawn and family excluded and patients isolated. People want to die in the comfort and familiarity of their own home, with the people they love and all the things that affirm them as people.

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