

SOME OF US ARE GOING TO NEED AID IN DYING.

[SLIDE BACKGROUND: Weighty topic]

*Notes for the 12/16/2015 Presentation at Meadowood
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[Ask all those who think they are NOT going to die someday to leave the room.]

Compassion & Choices

- Been around since 1980 and took the name Compassion & Choices in 2005.
- Indiana Chapter founded in 1989 in Bloomington.
- Our 2005 Mission Statement includes these principles and objectives:
 - We all deserve a peaceful death with dignity.
 - It is the right of mentally competent adults to have advance directives such as Living Wills and Do-Not Resuscitate orders.
 - Our final wishes should be clear and they should be understood and honored by our loved ones and health care providers.
 - We promote legalized physician-assisted aid in dying as practiced in Oregon and other states.

How did I come to be a supporter of Compassion & Choices?

- Suffering and slow, painful deaths of friends and relatives
 - Cousin Chloe Wiggins Brasher's agonizing last three days of life in 1995 at the age of 88.
 - Great Aunt Grace Juanita Seabay Sara Ella Oleta Dennis Jackson's slow decline with Alzheimer's, resulting in her death at age 88 in 1998.
 - My mother, Nell Crowley, who died in 2013 at the age 93, in effect by starving herself to death in a nursing home.

Dying in America

- About 2.6 million people died in the US in 2013.
- About half of those died quickly, but the other half died slowly with some pain.
- For 90%-98% of those, the pain is relievable; hospice gives wonderful help.
- What about the unlucky ones? Even if it is only 2% of all deaths in the US, that is over 50,000 people who suffer difficult deaths each year.
- 2% of the 60,000 deaths that occur in Indiana each year would be 1,200 people who potentially die agonizing deaths. This is the group we want to help through legislation that permits physician-assisted aid in dying.

End of Life Choices

- Full code: Fight death no matter what by using every means available, including feeding tubes, artificial nutrition, etc.) **This would have been my real dad's choice. He once told me he would use cryonic suspension if he could afford it.)**
- Passive Euthanasia (all legal in US): stopping treatment
 - “No Code” and No Feeding Tubes
 - No medical interventions (“pull the plug” and “let nature take its course.”)
 - Palliative (relieving or lessening pain or suffering without curing); Terminal Sedation
 - Voluntarily Stopping Eating and Drinking (VSED)
 - The U.S. Supreme Court has affirmed the right of a patient to refuse any medical treatment, including food and fluids.
 - When planned for and supported in the right circumstances, VSED can be a peaceful and gentle way of dying. (Death usually comes in 7-10 days.)
 - Many terminally ill patients naturally lose interest in eating and drinking as their illness progresses and may find that choosing to stop eating and drinking relieves their discomfort and other symptoms.
- Active Euthanasia (Not legal in US)
 - Dr. Jack Kevorkian
 - Permitted in Belgium, Netherlands, Luxembourg, and Switzerland (the only place in Europe where a foreigner can obtain the drugs, but in that case they must be self-administered.)
- Physician-Assisted Dying (PAD) (self-administered drugs prescribed by a doctor)
 - Five states now permit this (OR, WA, CA, MT, and VT)
 - Challenged by the Bush Administration in 2001 but upheld by the US Supreme Court in *Gonzalez v. Oregon* (US 2006).
 - Death usually occurs within one hour.

Objections to PAD

- It's Murder!
 - It is the patient's choice, whereas murder cuts off the life of an unwilling victim.
 - Voluntary and compassionate

- Hippocratic Oath: “Above all, do no harm.” -- In this case, physicians are healers by alleviating pain and suffering when true healing is no longer an option.
- It’s suicide
 - Suicide is the premature ending of life, sometimes because of temporary problems, and it is most often tragic.
 - Term “suicide” used as a weapon against aid in dying because of its negative connotations.
 - Calling it suicide automatically prejudices the conversation.
 - Different terms are used to describe the same event, depending on the circumstances: **SHOW** Byron Chell’s book Aid in Dying (The Clear Ethical Case for Physician Assisted Death): A shoots and kills B. Murder vs. justifiable homicide vs. manslaughter
 - Shortening the suffering and pain of the dying process is not tragic.
 - We use modern medicine to extend the duration and quality of life. Why not use it to ease the pain and suffering of the dying process and responsibly shorten a difficult death?
 - We treat our pets with more dignity and compassion than we do people.
 - At the beginning of life, we often induce labor and perform Caesarean sections to hasten difficult births; why then not use modern medicine to hasten difficult deaths?
 - With aid in dying, we have a person who wants to live, but is dying. In most cases of suicide, we have a person who could live, but wants to die.

Advance Directives

Indiana law specifies four specific advance directive forms.

- Life Prolonging Procedures Declaration
- Living Will Declaration
- Out-of-hospital Do Not Resuscitate Declaration and Order
- Physicians Order for Scope of Treatment (POST)

POST (Physician Orders for Scope of Treatment), effective July 1, 2013 onward

- Form has choices for life-sustaining treatments, including resuscitation and medical orders concerning:
 - comfort care
 - hospitalization
 - intubation
 - mechanical ventilation

- antibiotics
- artificially-administered nutrition.
- POST specifically intended for seriously ill persons with advanced chronic progressive illness, advanced chronic progressive frailty, or terminal conditions. (expected to die within one year)
- NOT for patients who are unlikely to benefit from cardiopulmonary resuscitation.
- NOT for those with functionally disabling problems who have many years of life expectancy.
- Does NOT replace a living will or medical power of attorney form.
- Must be reviewed and signed by a physician to be activated
- Also requires the signature of the patient or representative
- The POST form transfers throughout the health-care system, and the orders are valid in all settings.
- A health care provider is not required to comply with a patient’s POST form if the provider:
 - Believes it would be medically inappropriate to do so
 - Has religious or moral beliefs that conflict with the POST form orders. (In this case, they are required to coordinate the transfer of care to another health care provider who will carry out the orders.)

HANDOUT: Compassion & Choices of Indiana’s Advance Directive Package

- Very similar to the Indiana state form, but with much more informative.
- Includes “The Dementia Provision” page: covers the situation where the person suffers from severe dementia, but is neither unconscious nor expected to die within a short period of time.

HANDOUT: The Healthcare Decisions Game—A short quiz to find out how well you have communicated your healthcare wishes

- Five healthcare scenarios which are answered Yes, No, or Uncertain
- Take it yourself and compare your answers to those of the person who is your Durable Power of Attorney for Healthcare Matters.

Aid-in-Dying Legislation—Synopsis of the 2015 Sample Draft Legislation Provided by Compassion & Choices

The draft bill makes it legal for a mentally competent, terminally ill individual to request and obtain a prescription for medication that may be self-administered to end the individual’s life.

- The option to end one's life under this legislation is only available when an individual has been medically confirmed to be terminally ill, that is, suffering from an incurable and irreversible illness that will result in death within 6 months. Furthermore, the attending physician's diagnosis must be confirmed by a second consulting physician.
- The attending physician must make sure that the individual understands the risks associated with taking the medication and the probable result and is made aware of feasible alternatives or additional treatment options.
- Old age or disability alone is not sufficient to qualify for the option to end one's life under this legislation.
- Safeguards are built into the legislation to guarantee that a person is mentally competent and not being coerced to sign the request.
- Unless otherwise prohibited by law, the attending physician may sign the qualified individual's death certificate, listing the cause of death as the underlying terminal illness.
- The document contains in Section 9 (p. 13) a sample request form.
- Sections 11 and 12 restrict any attempts to invalidate wills, contracts, insurance or annuity policies, etc. because the individual has either made or rescinded a request for aid-in-dying medication.
- Sections 13 and 14 prohibit sanctions against any healthcare providers who participate in the procedure and guarantee a physician's right not to participate in the process.
- Sections 16 and 17 provide severe penalties for anyone who might forge a request or conceal or destroy a rescission.

For the full pdf document, see:

<https://www.compassionandchoices.org/userfiles/Guide-to-Legislation-with-web-links3.1.pdf>

(The Sample Draft State Legislation portion of the Compassion & Choices document begins on page 8.)

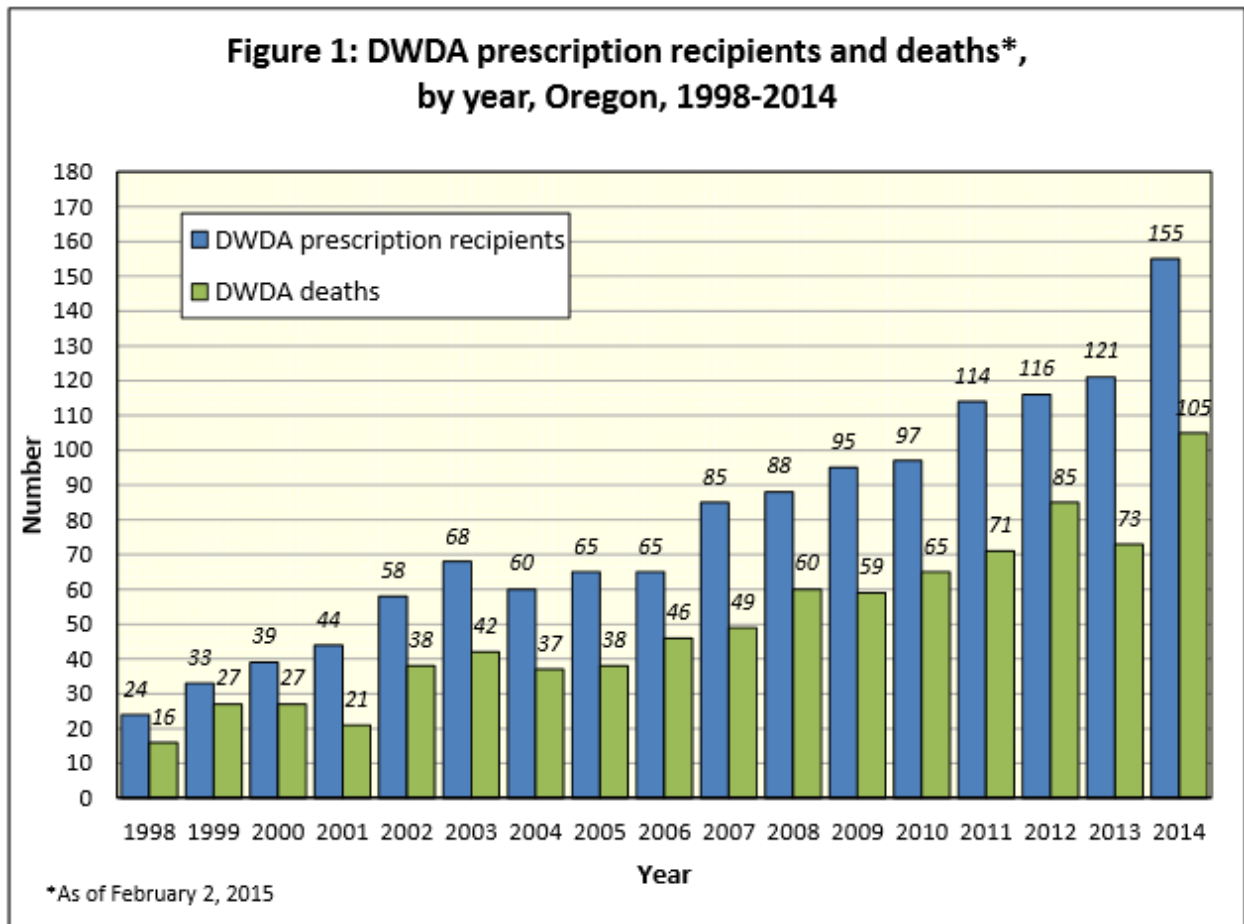
Data from Oregon

Oregon's Death with Dignity Act was enacted in late 1997. It allows terminally-ill adult Oregonians to obtain and use prescriptions from their physicians for self-administered, lethal

doses of medications. The Act states that “Actions taken in accordance with [this law] shall not, for any purpose, constitute suicide, assisted suicide, mercy killing or homicide, under the law.”

Most Recent Data is for 2014.

- 155 prescriptions written that year with 105 having died from the medications by the time the required report for 2014 was written by the Oregon Public Health Division.
- 1,327 people got prescriptions from 1998-2014, and 859 of those took the medications.
- In 2014 most (about 85%) had either cancer or Amyotrophic Lateral Sclerosis (Lou Gehrig’s Disease)
- Most frequently mentioned end-of-life concerns:
 - Loss of autonomy (91.4%)
 - Decreasing ability to participate n activities that made life enjoyable (86.7%)
 - Loss of dignity (71.4%)
- Prescribing physicians were usually not present at the time of death (there in only 14 cases).



SUMMARY

- The right of a mentally competent individual to make decisions concerning his or her own health treatments, including the refusal of treatment and, if so desired, the aid of a physician in accelerating death.
- “In the end, I was left to reflect on what I would want in the face of my own death.” --Jerry Brown, California governor on signing "right to die" legislation that allows doctors to prescribe life-ending medications to terminally ill patients. *Time* October 19, 2015, p. 8.
- It all boils down to a question of the quality of life. **[SHOW Exhaustipated slide]**

Notes

Byron Chell. *Aid in Dying: The Ultimate Argument* (The Clear Ethical Case for Physician Assisted Death) (2014)

Helene Starks, Denise Dudzinski, and Nicole White. “Physician Aid-in-Dying.” *Ethics in Medicine* (University of Washington School of Medicine) (Original text written by: Clarence H. Braddock III with Mark R. Tonelli (1998) <http://depts.washington.edu/bioethx/topics/pad.html> (accessed 14 December 2015).

Ronald M. Katz. Issues Impacting “End of Life” Choices. (Maximizing quality of life and minimizing pain and suffering when faced with end-of-life decisions.) (2/21/2014)

Clarke Miller. The Right to Die Well: Why Physician-Assisted Dying Should be Legal.

STATSINDIANA (Indiana’s Public Data Utility) <http://www.stats.indiana.edu/>

CDC National Vital Statistics System Mortality Data <http://www.cdc.gov/nchs/deaths.htm>

Oregon Health Authority. Oregon’s Death with Dignity Act—2014. <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year17.pdf>

Healthcare Decisions Game (from Compassion & Choices) <https://www.compassionandchoices.org/userfiles/Healthcare-Decisions-Game-Quiz-for-You.pdf>