“Death with Dignity” in the United States
History and Current Discussion

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Outline

- History-
  - A chronology of death and dying in America
  - Today’s concerns
    - Death with Dignity
  - Current Discussion
    - What you need to know as a person and health information resource
  - Future

Growing Up With “Death”
Growing Up With “Death”

Growing Up With “Death”

Growing Up With “Death”

I am not afraid of death, I just don’t want to be there when it happens.

— Woody Allen —
Jack Kevorkian and Assisted Suicide

- 1952 Medical school graduate with background in pathology
- 1958 Advocated for research in consenting convicts; U of M asks him to leave
- 1987 Advertises practice as a “physician consultant” for “death counseling”
- 1988 Article “The Last Fearsome Taboo: Medical Aspect of Planned Death”
- 1989 Builds first “suicide machine” for $30 with parts from garage sales and hardware store

Kevorkian Do It Yourself Machine

Not A Science Project Winner
1990 Assists in the death of Janet Adkins 54, a woman with Alzheimer’s disease with machine
1991 Michigan suspends his license
1994 Acquitted of assisted suicide
1998 Videotape shown on “60 Minutes” death of Thomas Youk, ALS patient; Kevorkian charged with murder
2007 Leaves prison in failing health
2011 Dies at 83 years of age
Foundations of Discussion

- **Definition of Terms**
  - Thanatology
  - Terminal prognosis, terminally ill
  - Advance directives
  - Euthanasia
  - Physician-assisted suicide
  - Aid in dying
  - Death with dignity

Word Definitions Matter

- **Euthanasia**: Literally “peaceful dying,” but in practice an act taken by another that ends the life of the patient. Can be voluntary (at the patient’s request) or involuntary (capital punishment).
  - ILLEGAL in healthcare setting

- **Assisted Suicide**: The act of assisting someone who is *not* terminally ill and/or not mentally competent in ending his/her own life.
  - ILLEGAL throughout the U.S.

Physician Assisted Suicide (PAS)

- Can be seen as a combination of euthanasia and suicide; It resembles active euthanasia in that the doctor acts to bring about the death but the causation of the doctor is indirect
- The AMA opposes assisted suicide but several appeals courts have upheld the practice on privacy grounds
“Assisted Suicide” rejected by
- American Academy of Hospice and Palliative Medicine (AAHPM)
- American Public Health Association (APHA)
- American Medical Women’s Association
- American College of Legal Medicine
- American Medical Student Association
- Washington State Psychological Association

Physician Aid in Dying (PAD)
- Physician Aid in Dying: The act whereby a qualified terminally ill patient self-administers life-ending medication provided by a physician. Unlike suicide, the person is going to die and curative treatment is not available. (American Public Health Association terminology)
- Physician-Assisted Death: AAHPM
- Death with Dignity: Term used in Oregon, Washington and Vermont to indicate legislation that codifies the practice

Legal Definition (PAD)
- The law allows a mentally competent, terminally-ill adult with a prognosis of 6 months or less, to self-administer a lethal dose of medication obtained from a medical or osteopathic physician
- Must complete the requirements of the process as outlined in the law
Healthcare Professional Associations
Recognizing Medical Aid in Dying

**Associations**
- California Medical Association
- American Medical Student Association
- American Public Health Association
- American Medical Women’s Association
- American College of Legal Medicine
- American Academy of Hospice & Palliative Medicine

Polling Terms
Support for Physician-Assisted Suicide – Two Question Wordings
(Framed A) When a person has a disease that cannot be cured, do you think doctors should be allowed by law to end the patient’s life by some painless means if the patient and his or her family request it?

(Framed B) When a person has a disease that cannot be cured and is living in severe pain, do you think doctors should or should not be allowed by law to assist the patient to commit suicide if the patient requests it?

- “End the patient’s life by some painless means”
- “Assist the patient to commit suicide”

Defining Terms
Medical Aid in Dying
- People have a terminal illness and want to live
- Understand that their condition is no longer treatable — there is no hope for a better outcome
- People seeking aid in dying are deliberate in their request and involve family in discussions with physicians, reflecting a consideration process

“Assisted Suicide”
- Person has no terminal illness, but wants to die
- They see no hope and do not recognize that their problems are treatable
Options for Care and Choice
- Pain and symptom management
- Hospice
- Voluntarily Stopping Eating and Drinking (VSED)
- Declining or stopping life-sustaining treatment
- Medical aid in dying
- Palliative/terminal sedation

Doctrine of Double Effect
- Where an action, intended to have a good effect, can achieve this effect only at the risk of producing a harmful/bad effect, then this action is ethically permissible providing:
  - The action is good itself
  - The intention is solely to produce the good effect (even though the bad effect may be foreseen)
  - The good effect is not achieved through the bad effect
  - There is sufficient reason to permit the bad effect (the action is undertaken for a proportionately grave reason)

Aid in Dying Organizations
- 1967 Euthanasia Education Council
- 1978 Concern for Dying
- 1980 World Federation of Right to Die Societies
- 1980 Hemlock Society
  - Author Derek Humphry “Last Exit”
- 2002 End of Life Choices
- 2003 Compassion in Dying Federation
- 2007 Compassion and Choices
Aid in Dying Organizations: Compassion & Choices

- 1994 Oregon voters approve the Oregon Death with Dignity Act (DWDA)
- 2007 End-of-Life Choices merges with Compassion in Dying to form Compassion & Choices
- 2006 Medical associations begin to adopt policies that support aid in dying, including American Women’s Medical Association, the American Public Health Association and The American Medical Students’ Association

Aid in Dying Organization: Compassion & Choices (cont)

- 2008 Washington voters approve Death with Dignity Act by a margin of 59% to 41% becoming 2nd state
- 2009 Montana Supreme Court rules in favor of case affirming that it is not against Montana public policy for a physician to provide medical aid in dying
- 2013 Vermont becomes the fourth state to authorize aid in dying and the first to do so through the legislature
- 2014 New Mexico authorizes medical aid in dying via a court case
- 2014 Brittany Maynard, a terminally ill 29-year old Californian, releases video

Aid in Dying Organization: Compassion & Choices (cont)

- 2015 Twenty-five state legislatures and the District of Columbia introduce medical-aid-in dying bills
  - Bipartisan Care Planning Act of 2015 introduced to allow Medicare benefit for people facing grave illness to work with their doctors
  - California Medical Association drops 28-years opposition to medical aid-in-dying by taking a neutral position on the End of Life Option Act
  - New Mexico Court of Appeals issues a decision finding that there is NO fundamental right to aid in dying in New Mexico reversing 2014 ruling
Aid in Dying Organization: 
Compassion & Choices (cont)

2015 (cont)
- California becomes the fifth state to authorize medical-aid-in-dying by passing End of Life Option Act
- Centers for Medicare & Medicaid Services (CMS) issues a rule to reimburse doctors for advance planning and end-of-life conversations

2016 Colorado becomes the sixth state to authorize medical aid in dying with the End-of-Life Options Act
- 2016 District of Columbia is poised to follow Colorado to become the seventh jurisdiction where medical aid in dying is authorized

History of Oregon Law

- Oregon Death with Dignity Act (DWDA) was a citizen’s initiative passed in November 1994 with 51% in favor
- Stopped by an injunction but lifted in October 1997
- In November 1997, a measure asking Oregon voters to repeal the DWDA
  - It was defeated 60% to 40% retaining the DWDA making Oregon the first state allowing this practice

Challenges to Oregon’s DWDA

- Challenged by attorney general John Ashcroft who called doctor assisted suicide “not a legitimate purpose” for prescribing drugs and vowed to prosecute Oregon doctors (and pharmacists!) he said were violation the Controlled Substance Act (CSA) of 1970
  - In 2006, a 6-3 decision by the US Supreme Court upheld the DWDA Oregon law
  - Noted that the DEA in their attempt to discipline physicians by using the CSA, were in effect, “practicing” medicine
  - The court noted that the practice of medicine is regulated by the states, not the DEA
Oregon’s Requirements for End of Life Medication

- Residents must be age 18 or older
- Must be capable of making and communicating health-care decisions
- Must be suffering from a terminal disease that will lead to death within six-months
- The request must be signed by at least two witnesses, one of whom cannot be a relative, the patient’s doctor nor a person entitled to any portion of the patient’s estate
- The patient must wait 15 days before getting the prescription
- A patient can rescind a request at any time

Timetable for Completing Eligibility Process

- **Day 0**
  Patient makes 1st oral request to a physician; if not to the doctor who will be AP, the charted request needs to be obtained by AP

- **Up to Day 13 or later**
  After AP and CP have seen the patient, accepted the 1st oral request, and certified the patient as eligible under the DWDA, the patient may submit the Written Request for Medication To End My Life Form to the AP

- **Day 15 or later**
  AP may write prescribe medicines after receiving both oral requests, and if at least 48 hours have passed after receiving the Written Request for Medication To End My Life Form

**AP** = Attending Physician **CP** = Consultant Physician
Request for Medication To End My Life

Experience with Oregon DWDA

Death With Dignity Act

The number of people using the Death With Dignity Act has climbed in the past decade. In 2007, 85 prescriptions were written and 65 people died because of those medications. In 2010, 13, were alive at the end of 2007, 24 had died of their underlying disease. A total of 141 Oregonians have died under the terms of the law since its inception, six in Multnomah County, three in Columbia County and none in Clackamas County.

Experience with Oregon DWDA

Figure 1: DWDA prescription recipients and deaths*, by year, Oregon, 1998-2015

*As of January 31, 2014
Motivation for PAD
- Desire to control circumstances of death
- Die at home
- Maintain independence
- Avoid future physical symptoms
- Seekers tend to be:
  - Active, independent/anti-dependent types
  - Long-time believers in self-determination
  - Pragmatic, take-charge people
  - Less interested in quantity of life than in quality of life
- Seekers seem greatly palliated by knowing that the option is accessible on demand

Arguments Against Physician Assisted Death
- Sanctity of life
- Harmful consequences
  - Vulnerable populations would be adversely affected
  - The "Slippery Slope" or broadening of application of the law
  - Improper regulation with patient coercion
  - Quality of Palliative Care would suffer
Arguments Against: Harmful Consequence

#1 Vulnerable Populations

- It was predicted that there would be improper overuse in vulnerable populations
- Those who have used the law are disproportionately:
  - Financially secure
  - Educated
  - Non-minority

#2 The “Slippery Slope”

- Many predicted that the law would be broadened to include anyone who wanted to die for any reason
- The same classes of patients are eligible in Oregon and Washington
- No serious efforts to extend the law to other populations or other practices (such as euthanasia) have occurred

#3 Improper Regulation

- Predicting that patients would receive aid in dying when not competent, that there would be abuse (patient coercion)
- Multiple requirements:
  - Two physicians with face to face evaluation
  - Psychological evaluation if physician believes judgment may be impaired
  - Patient maintains control: may rescind request, not fill prescription, not take medication and must self-administer
- No convincing evidence for abuse
Arguments Against: Harmful Consequence #4 Palliative Care Would Suffer

- Predicted that efforts to relieve symptoms of the terminally‐ill would decrease
- Quality of Palliative Care in Oregon has increased since law’s passage
- Physicians have made deliberate effort to improve knowledge of PC
- Forced a discussion of treatment options at end of life
- 90% of patients who use the law are on hospice
- Inadequate palliative care is not a significant motivation for requesting aid in dying

Experience with DWDA


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<thead>
<tr>
<th>Reason</th>
<th>Oregon</th>
<th>Washington</th>
</tr>
</thead>
<tbody>
<tr>
<td>loss of autonomy</td>
<td>91%</td>
<td>91%</td>
</tr>
<tr>
<td>loss of dignity</td>
<td>81%</td>
<td>80%</td>
</tr>
<tr>
<td>loss of quality</td>
<td>89%</td>
<td>87%</td>
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</tbody>
</table>

Experience with DWDA

Cumulative Experience in OR and WA: Prescriptions Written and Deaths

<table>
<thead>
<tr>
<th>State</th>
<th>Oregon</th>
<th>Washington</th>
</tr>
</thead>
<tbody>
<tr>
<td>Years</td>
<td>1998-2013</td>
<td>2009-2013</td>
</tr>
<tr>
<td>Prescriptions written</td>
<td>1,173</td>
<td>647</td>
</tr>
<tr>
<td>Patients died after ingesting medication</td>
<td>752</td>
<td>359</td>
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</tbody>
</table>
Renewed Discussion

Brittany Maynard’s “Death With Dignity”

What Constitutes a Good Death?

- Symptom management
- Treatment in accord with patient wishes
- Psychological health
- Spiritual and existential well-being
- Social support
- Experience of Death
Barriers to A Good Death

- Education, money, inability to navigate the system
- Healthcare only works well five days a week
- Physician ignorance; Myths of pain management
- Inadequate staff training
- Conflict amongst family members
- Lack of qualified staff

The Good Death

![The Good Death book cover](image)

What Constitutes a Good Death?

There is no good death, I know now. It always hurts, both the dying and the left behind. But there is a good enough death . . . each specific to the person dying. As they wish, as best they can.

-Ann Neumann, THE GOOD DEATH
When Death Becomes Air

Being Mortal

Modern Death
**Advance Care Planning**

- Types of advanced directives
  - Living Wills: Identify types of treatment a patient wants or does not want if they are terminally ill or in a vegetative state and lack decision-making capacity
  - Health Care Proxy: Identifies a surrogate to make decision when the patient lacks decision-making capacity

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**Advanced Directives**

- [Website](https://www.azsos.gov/services/advance-directives)

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**POLST: Advance Care Planning for Seriously Ill**

- POLST (Physician Orders for Life-Sustaining Treatment)
  - Is not an advance directive but an actionable medical order ONLY for seriously ill patients for whom their HCP would not be surprised if they died in the next year
  - Would be inappropriate for a HCP to complete a POLST form for a patient who is outside the intended POLST population
  - Used in *combination* with Advance Directives
**POLST and Advance Directives**

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>POLST</th>
<th>Advance Directives</th>
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</thead>
<tbody>
<tr>
<td>Population</td>
<td>For the seriously ill</td>
<td>All adults</td>
</tr>
<tr>
<td>Time frame</td>
<td>Current care</td>
<td>Future care</td>
</tr>
<tr>
<td>Who completes the form</td>
<td>Health care professionals</td>
<td>Patients</td>
</tr>
<tr>
<td>Resulting form</td>
<td>Medical orders (POLST)</td>
<td>Advance directive</td>
</tr>
<tr>
<td>Health care agent or</td>
<td>Can engage in discussion if patient lacks capacity</td>
<td>Cannot complete</td>
</tr>
<tr>
<td>surrogate role</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Portability</td>
<td>Provider responsibility</td>
<td>Patient/family responsibility</td>
</tr>
<tr>
<td>Periodic review</td>
<td>Provider responsibility</td>
<td>Patient/family responsibility</td>
</tr>
</tbody>
</table>

POLST = Physician Orders for Life-Sustaining Treatment

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**Self Empowerment**

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“What’s wrong with death sir? What are we so morally afraid of? Why can’t we treat death with a certain amount of humanity and dignity and decency and God forbid, maybe even humor.” — Patch Adams
Summary

- History-
  - A chronology of death and dying in America
- Today's concerns
  - Death with Dignity
- Current Discussion
  - What you need to know as a person and health information resource
- Future