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Care and Choice at the End of Life

A Physician's Perspective on Medical Aid in Dying

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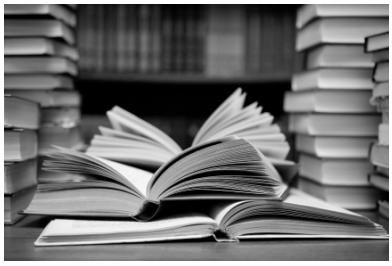
"Life is meaningful because it is a story …

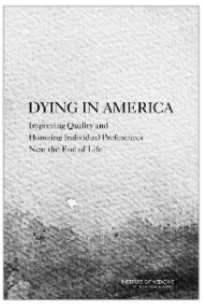


… and in stories, endings matter.

~Atul Gawande, Being Mortal

Institute of Medicine

Dying in America
Improving Quality and
Honoring Individual Preferences
Near the End of Life



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End-of-Life Options

- Pursuing Life-Sustaining Treatment
- Refusing Treatment
- Discontinuing Treatment
- Hospice
- Voluntarily Stopping Eating and Drinking (VSED)
- Palliative Sedation
- Medical Aid in Dying

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Medical aid in dying is a medical practice in which a terminally ill, mentally capable adult with a prognosis of six months or less to live may request from her or his doctor a prescription for medication which she or he can choose to self-ingest to bring about a peaceful death.

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Majority of Americans and Doctors Support Medical Aid in Dying as an End of Life Option

- 68-74% of Americans agree with access to medical aid in dying (Gallup 2015, Harris 2014)
- 56% of Colorado Medical Society members agree with access to medical aid in dying (2016)

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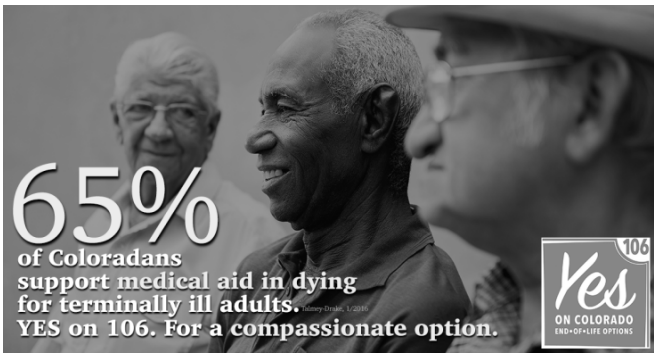
Colorado End-of-Life Options Act



Coloradans overwhelmingly authorized medical aid in dying on November 8, 2016.

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Where Medical Aid in Dying Is Authorized

Oregon, 1997, by ballot initiative

Washington, 2008, by ballot initiative

Montana, 2009, by court ruling

Vermont, 2013, through legislation

California, 2015, through legislation

Colorado, 2016, by ballot initiative

District of Columbia, 2017, through legislation

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Colorado End-of-Life Options Act: Eligibility Requirements

- Adult
- Terminally ill
- Prognosis of 6 months or less
- Mentally capable of making informed medical decisions

Regulatory Requirements include:

- State resident
- Self-administer the medication (voluntary, conscious, and physical act to take the medication into the body)

Physician Components

Prescribing Physician ("Attending")

Evaluate patient

Prescribe medication

Complete forms

Consulting Physician

Evaluate patient

Complete forms

Psychiatrist/Psychologist

Consulted for an evaluation of an active mental illness that may effect patient's ability to understand informed consent or have full mental capacity

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CO EOLOA - Request Requirements

- Two oral requests from patient at least 15 days apart (not necessarily in person, but must confirm voluntariness of the person's request outside of the presence of a third party)
- One statutory form written request signed by two witnesses (attending doctor can't be a witness, but at least one witness can't be employed at a facility where person is a patient/resident) - any order of requests

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Attending Physician Responsibilities

1. Determine diagnosis, prognosis, capability, and voluntariness of request.
2. Refer to consulting physician to confirm #1.
3. Ensure informed decision-making.
4. Refer to a psychologist/psychiatrist if unsure of capability
5. Counsel person of importance of safe-keeping of medication, notifying kin and having a person present when taking the medication

Attending Physician Documentation Requirements

1. Document in medical record
2. File a dispensing record with CDPHE
3. Fulfill any other reporting requirements that CDPHE may require in the future, such as a form

Consulting Physician Responsibilities

1. Examine the patient
2. Confirm in writing the patient's diagnosis, prognosis, capability and making an informed decision
3. Refer the patient to a psychologist/psychiatrist if unsure of capability and document such

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Liability/Professional Protections

- No duty to participate
- No liability for medical providers if act in good faith under the EOLOA
- No disciplinary action taken against a licensed physician by any state medical boards for participation or declining to participate

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Other Protections

- The choice to request/take aid-in-dying medication cannot affect health or life insurance status or contracts.
- Death certificate must list underlying terminal illness as the cause of death. (Attending physician or hospice medical director shall sign)
- Medical aid in dying does not constitute suicide, mercy killing or homicide under the law.

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Medical Aid in Dying in Practice

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Clinical Criteria for Medical Aid in Dying

Aid-in-Dying Medication

- The type and dosage of aid-in-dying medication prescribed for the terminally ill person can vary with each individual.
- After self-administering the medication, the person usually falls asleep with 20 minutes and dies painlessly and peacefully within an hour or two.

Medications

NPO for 4 – 6 hours (no dairy, no heavy laxatives)
Take Usual medications
One hour prior
Ondansetron 8 mg
Metoclopramide 20 mg
Secobarbital 10 Gm (#100, 100 mg capsules)
Broken apart, crystals placed in glass, mixed with 3 – 4 oz of room temperature water
(Must be ingested in less than 90 seconds)

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Medications

For opioid naïve patients:
Rapid acting morphine sulfate
(**Roxanol®**) 1,800 mg
3 bottles (600 mg/btl)

DDMP (compounded) Diazepam 1 Gm; Digoxin 50 mg; MS 15 Gm; Propranolol 2 Gm

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20 Years of Practice in Oregon Show that Medical Aid in Dying Works as Intended

1. Just having a prescription (on hand) for aid-in-dying medication is a comfort.
2. People use the law because of loss of dignity, because of autonomy, because of anhedonia, to minimize pain and suffering.
3. The elderly, people with disabilities, and people of color have not been coerced or abused.

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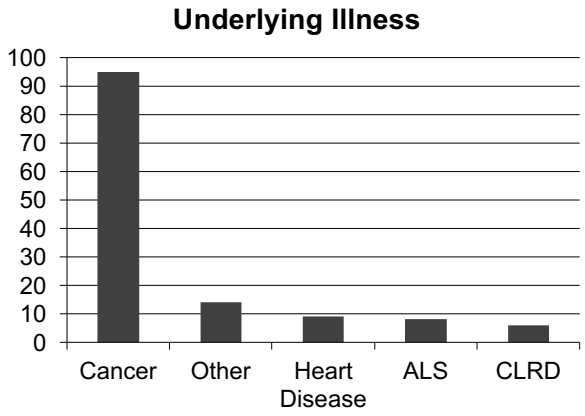
Diagnosis of People Who Used the Death With Dignity Law in Oregon



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Concerns Patients Have which Lead to Use of Oregon's Death with Dignity Law

96%	Less able to engage in activities that make life enjoyable
92%	Loss of autonomy
75%	Loss of dignity

Observations

- More Oregon physicians are involved in DWD (aid in dying) as attending and/or consulting physicians
- More Oregon hospices are "engaged"
- Medical aid in dying is more integrated and normalized
- Health systems are identifying "Navigators"
- Many barriers still exist

Having a Prescription for Aid-in-Dying Medication Is a Comfort

Only 64% of the 1,545 prescriptions written between 1998 and 2015 were actually used.

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Medical Aid in Dying Is <u>Not</u> Suicide

By law, medical aid in dying is <u>not</u> considered suicide, assisted suicide, homicide or euthanasia

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Medical Aid in Dying vs. Suicide

	State of Wellness	State of Mind	State of Action
Suicide	PHYSICALLY HEALTHY	EMOTIONAL; DEPRESSED	IMPULSIVE
Medical Aid in Dying	TERMINAL: 6 MONTHS TO LIVE	RATIONAL; REALISTIC	THOUGHTFUL WITH SAFEGUARDS

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How Medical Aid in Dying Compares to Suicide and Suffering Death

	Time to Plan	Place of Death	Time of Death	Choices
Sudden Death (Untimely)	NO	NO	NO	NO
Protracted Death (Painful to Patient and Family)	YES	POSSIBLY	NO	SOME
Medical Aid in Dying	YES	YES	YES	YES

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Medical Aid in Dying Is Not Suicide

Medical Aid in Dying	Suicide
Terminal Diagnosis	No Terminal Diagnosis
Mental Capacity	Mentally Incapable (psychiatric diagnosis)
Patient **wants** to **live**	Patient **wants** to **die**
Planned; with family	Impulsive; alone
Death is 'gentle'	Death may be violent
Normal grieving after death (guilt is rare)	Abnormal grief (family members wonder "what if?")

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Health Insurance

Federal prohibition:

- Medicare
- VA

Most private insurance pays

State Medicaid may pay in the future

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Integration of Medical Aid in Dying

Annals of Internal Medicine

IDEAS AND OPINIONS

A Call for a Patient-Centered Response to Legalized Assisted Dying

John Frye, MA, and Stuart J. Youngner, MD

On 9 June 2016, California became the fifth state to legalize physician-assisted suicide (PAS), joining Oregon, Washington, Montana, and Vermont. More states may soon follow. Like it or not, PAS is here and is not going away. Given this reality, it is problematic that professional organizations have left physicians without sufficient support and guidance on how to provide the best possible care to dying patients seeking to exercise this legal right.

willing to communicate with others in their practices and profession (2). Beyond such personal considerations, the primary physician must identify a consulting physician to confirm the patient's prognosis and decision-making capacity. Ideally, the consultant is independent; however, in the absence of guidance on how to choose a consultant, primary physicians may worry about the consultant's political stance or familiarity and experience with end-of-life decision making.

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Engaged Neutral Stance Toward Medical Aid in Dying

Table. Studied Versus Engaged Neutrality by Medical Associations

Topic	Studied Neutrality	Engaged Neutrality
Should laws allowing PAS be enacted?	Neutral	Neutral
Should physicians follow their conscience in responding to patient requests for PAS?	Yes	Yes
Does the association support palliative and hospice care for patients requesting PAS?	Yes	Yes
Should medical associations provide additional training/education for physicians?	No position	Yes
Does the association train or provide skilled consultants available for any physician?	No position	Yes
Does the association encourage the formation of institutional policies that ensure proper support for physicians and patients after PAS is requested?	No position	Yes
Does the association support or lobby for support of research into and continuous improvement of assisted dying and end-of-life care practices?	No position	Yes

PAS = physician-assisted suicide.

An engaged neutral stance can better help clinicians responsibly meet the needs of their patients while still respecting the diverse opinions about medical aid in dying.

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Hospice and Palliative Care Are Improved and Better Utilized

- 92% enrolled in hospice
- 90% died at home

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Positive Impact on Palliative Care

According to a 2015 article in the Journal of Palliative Medicine, the Oregon Death With Dignity Act may have resulted in

" … more open conversation and careful evaluation of end-of-life options, more appropriate palliative care training of physicians, and more efforts to reduce barriers to access to hospice care and has thus increased hospice referrals and reduced potentially concerning patterns of hospice use in the state."

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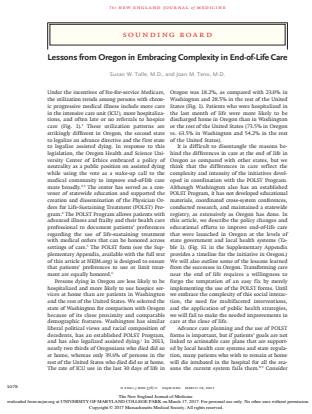
Persons dying in Oregon are less likely to be hospitalized and more likely to use hospice services at home than are persons in … the rest of the United States

Tolle, NEJM March 2017



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Lessons from Oregon in Embracing Complexity in End-of-Life Care

Susan W. Tolle, M.D., and Joan M. Teno, M.D.

Under the incentives of fee-for-service Medicare, the utilization trends among persons with chronic progressive medical illness include more care in the intensive care unit (ICU), more hospitalizations, and often late or no referrals to hospice care (Fig. 1).[1] These utilization patterns are strikingly different in Oregon, the second state to legalize an advance directive and the first state to legalize assisted dying. In response to this legislation, the Oregon Health and Science University Center of Ethics embraced a policy of neutrality as a public position on assisted dying while using the vote as a wake-up call to the medical community to improve end-of-life care more broadly.[2] The center has served as a convener of statewide education and supported the creation and dissemination of the Physician Orders for Life-Sustaining Treatment (POLST) Program.[3] The POLST Program allows patients with advanced illness and frailty and their health care professional to document patients' preferences regarding the use of life-sustaining treatment with medical orders that can be honored across settings of care.[4] The POLST form (see the Supplementary Appendix, available with the full text of this article at NEJM.org) is designed to ensure that patients receive either the care or limits treatment are equally honored.[5]

Persons dying in Oregon are less likely to be hospitalized and more likely to use hospice services at home than are patients in Washington and the rest of the United States. We selected the state of Washington for comparison with Oregon because of its close proximity and comparable demographic features. Washington has similar liberal political views and racial composition of decedents, has an established POLST Program, and has also legalized assisted dying.[6] In 2013, nearly two thirds of Oregonians who died did so at home, whereas only 30.6% of persons in the rest of the United States who died did so at home. The rate of ICU use in the last 30 days of life in Oregon was 18.2%, as compared with 23.0% in Washington and 28.5% in the rest of the United States (Fig. 2). Patients who were hospitalized in the last month of life were more likely to be discharged home in Oregon than in Washington or the rest of the United States (71.5% in Oregon vs. 63.5% in Washington and 54.2% in the rest of the United States).

It is difficult to disentangle the reasons behind the differences in care at the end of life in Oregon as compared with other states, but we think that the differences in care reflect the complexity and intensity of the initiatives developed in coordination with the POLST Program. Although Washington also has an established POLST Program, it has not developed educational materials, coordinated cross-system conferences, conducted research, and maintained a statewide registry, as extensively as Oregon has done. In this article, we describe the policy changes and educational efforts to improve end-of-life care that were launched in Oregon at the levels of state government and local health systems (Table 1). (Fig. S1 in the Supplementary Appendix provides a timeline for the initiative in Oregon.) We will also outline some of the lessons learned from the Oregon experience. We acknowledge that the end of life requires a willingness to forgo the temptation of an easy fix by merely implementing the use of the POLST forms. Until we embrace the complexity of this social intervention, the need for multifaceted interventions, and the application of public health strategies, we will fail to make the needed improvements in care at the close of life.

Advance care planning and the use of POLST forms is important, but if patients' goals are not linked to actionable care plans that are supported by local health care systems and state regulation, many patients who wish to remain at home will die imshared in the hospital for all the reasons the current system fails them.[7] Consider

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Positive Impact on Doctor-Patient Relationship

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Patient Autonomy

What is the physician's duty?

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Opinion

- **<u>Medical aid in dying is not a failure of palliative care or hospice care</u>**
- Hospice medical directors, social workers, nurses, and staff should be familiar with the process of medical aid in dying, the barriers, and the medications, etc.
- Hospices should develop polices regarding their clients who request medical aid in dying
- Hospices should respond professionally to all inquiries about end of life choices
- Hospices should adopt an "engaged" neutral position

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Medical Ethics

- *Primum non nocere* (do no harm)
- Professionalism ("putting the patient first")
- Professional integrity vs. personal beliefs
- Referral?

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One does not ask of one who suffers: What is your country and what is your religion?

One merely says: You suffer, this is enough for me; you belong to me and I shall help you.

LOUIS PASTEUR 1886

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Colorado Access Campaign Resources:

- ✓ **www.CompassionAndChoices.org/Colorado**
  - Videos for doctors and patients
  - Clinical criteria + fact sheets
  - State forms
  - Request a Speaker
  - **Find Care Tool** that lists facilities' policies
- ✓ Doc2Doc consultation service 800-247-7421
- ✓ Pharmacist2Pharmacist consultation service

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