

ASSISTED DYING IN OREGON

Twenty years of a safe and effective law

“The Death with Dignity Act is widely considered a success in Oregon. It’s part of how the state defines itself: as pioneering, stubbornly independent and deeply compassionate.”

CAMPAIGN FOR
DIGNITY
IN DYING.

What we can learn from Oregon

HIGHLIGHTS

- Oregon has had a safe and effective assisted dying law for 20 years (page 3)
- Past opponents of assisted dying now support the law (page 6)
- Assisted dying is embedded in clinical practice (page 7)
- The Oregon Hospice and Palliative Care Association supports patients' right to access this option (page 8)
- Religious leaders recognise the law works well (page 9)
- Palliative care has flourished alongside assisted dying (page 10)
- Upfront safeguards protect the public and prevent coercion (page 11)
- The evidence from Oregon has convinced legislators around the world to make assisted dying a legal option (page 14)

The law and process in Oregon

In October 1997, Oregon enacted the Death with Dignity Act². In the 20 years since, this has proved to be a safe and trusted medical practice. The law allows a dying adult with mental capacity, and a prognosis of six months or less to live, to request that their doctor prescribe them medication that they can choose to self-ingest to bring about a peaceful death.

To be eligible for an assisted death, the person must be³:

- 18 years of age or older, currently resident in Oregon
- mentally competent to make and communicate healthcare decisions for themselves and
- be diagnosed with a terminal illness that will lead to death within six months

The process:

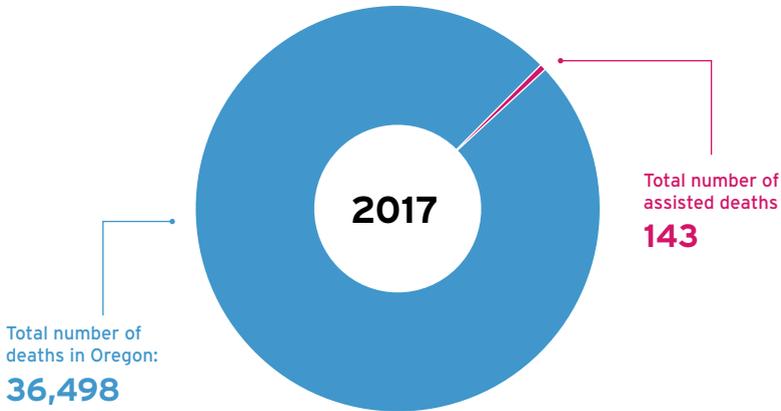
- The person must make an oral request for the medication. This usually happens when discussing end-of-life options with their doctor (referred to as the attending physician);
- Their doctor will then go through the requirements of the law; will determine the person's diagnosis and prognosis; and will also inform the person of feasible end-of-life options including comfort care, hospice care, and pain control;
- The person must then make a second oral request no less than 15 days after the first request and complete a written form which needs to be signed in the presence of two witnesses;
- A second doctor (known as the 'consulting doctor') must confirm that the person has a terminal illness with less than 6 months to live and has met the eligibility criteria;
- Both doctors must determine whether the person has capacity to make and communicate their own healthcare decisions;
- If either doctor is unable to determine whether the person has capacity to make the request, a mental health professional must evaluate the person and ensure that they are mentally competent to make healthcare decisions;
- The law requires that the terminally ill person self-administers the medication.

A person can withdraw their request at any time in any manner.

An effective and safeguarded law

The numbers

- There has been a small and steady rise in deaths since 1997 when assisted dying for terminally ill, mentally competent adults was legalised⁴. Between 1997 and 2017, there have been 1,275 assisted deaths.
- In 2017, assisted deaths accounted for 0.4% - or 1 in 250 - of all deaths in Oregon.



The people

- People who seek an assisted death are most often aged between 65 and 84, white, have a 'good education', have medical insurance and have cancer.
- Research demonstrates that groups of potentially vulnerable people are not negatively impacted by the law. People over 85, those with a lower socio-economic status and those suffering from psychiatric illness do not disproportionately use the assisted dying law⁵.

The end-of-life concerns

- Around 35% of people who go through the process and are given the prescription choose not use it. In many cases, they have the prescription as ‘emotional insurance’⁶.
- As part of the data-collection process⁷, people who have an assisted death in Oregon can cite their end-of-life concerns. The vast majority of people who have an assisted death in Oregon cite the loss of their autonomy (90.9%) and their being less able to engage in activities making life enjoyable (89.5%) as concerns, while three-quarters (75.7%) have concerns about losing dignity at the end of life.
- Other concerns, including that of being a burden on family, friends and caregivers, are cited by fewer than half of those who make use of the law, and almost always in conjunction with other, more frequently-cited concerns. None of the concerns are qualifying criteria but they are illustrations of concerns shared in common by all dying people⁸.

“Many [Oregonians] simply want to know that, if it gets so bad that they can’t tolerate it, the choice is there for them. There is a comfort in knowing it’s there.”⁹

Barbara Roberts, *former Governor of Oregon*

Reactions to the law

Public support

- 73% of U.S. adults agree that when a person has a disease that cannot be cured, doctors should be allowed by law to end the patient's life by some painless means if the patient requests it. This majority support is reflected across demographics, including respondents who attend church weekly (55%)¹⁰.
- In Oregon, even those initially opposed to the law, soon understood the value of this compassionate end-of-life option.

“Not only did I change my views, but I filibustered in the Senate to protect it [the Death with Dignity Act]. I consider it one of the most important things I’ve done in my time in public service.”¹¹

Ron Wyden, former Oregon Congressman and U.S. Senator

Healthcare professionals

ASSISTED DYING HAS BECOME EMBEDDED IN CLINICAL PRACTICE

The number of physicians supporting choice at the end of life has steadily increased. In 2017, 92 doctors wrote prescriptions for 218 people¹².

NUMBER OF PHYSICIANS WRITING PRESCRIPTIONS



THE OREGON HOSPICE AND PALLIATIVE CARE ASSOCIATION SUPPORTS THE RIGHTS OF OREGONIANS TO CHOOSE ANY AND ALL LEGAL END-OF-LIFE OPTIONS¹³

- The Oregon Medical Association¹⁴ and the Oregon Nurses Association¹⁵ are neutral on the issue of physician assisted death, and support their members to participate in line with their individual values.
- The American Public Health Association supports the choice of assisted dying and endorses the safeguards in the Oregon Death With Dignity Act¹⁶.
- As of 2017, 57% of US physicians say they believe medical aid-in-dying should be available to terminally ill people. A growing number of medical societies, including the California Medical Association, have dropped their opposition to the practice and have adopted a neutral stance¹⁷.

Religious leaders

- Leaders from a number of faith communities and organisations have voiced their support of the full range of end-of-life care options.

“We also affirm that one of the greatest gifts God has given us as humans is the freedom to seek to live in dignity according to one’s own beliefs and faith. For many terminally ill persons faced with inevitable and unavoidable death, the growing death with dignity movement now provides such freedom.”¹⁸

United Methodist church of the California-Pacific region

- Even those opposed to the law on faith grounds admit that it works well.

“If the bill was on the ballot this November, I still would not vote for it. My view of suicide has not changed. But in terms of the law working well in Oregon - I feel it has.”¹⁹

Rodney Page - former Executive Director of Ecumenical Ministries of Oregon

- Several faith leaders serve on the Advisory Board of Compassion & Choices, the oldest and largest, non-profit organization in the United States committed to improving care and expanding options for the end of life²⁰.

Twenty years of safeguarded patient choice

Palliative care has flourished alongside assisted dying

Oregon is within the top quartile of overall hospice use across the country^{21,22}.

Many studies have suggested the possibility that the Oregon Death with Dignity Act has contributed to 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 accessing hospice care. It has also been observed that requests for assisted dying often facilitated discussion of important issues, and many physicians felt that the process increased their confidence and assertiveness in discussing end-of-life issues with other patients^{24,25,26,27}.

Everyone in Oregon is encouraged to complete a Physician Orders for Life-Sustaining Treatment (POLST) form which records their wishes for or refusal of medical treatment in the event emergency medical services are required. Over 56,000 forms were completed in 2016²⁸ which demonstrates that all end-of-life care options are openly discussed and that assisted dying is considered just one of the many options available to dying people.

OVER 90%

**OF ADULTS WHO
USE MEDICAL
AID-IN-DYING
PRESCRIPTIONS
ARE ENROLLED
IN HOSPICE CARE** ²³

BETTER AND MORE HONEST CONVERSATIONS HAVE BEEN FACILITATED BY LAW CHANGE

Evidence shows that these open conversations are far more likely to reassure a dying person rather than direct them towards making a request for medical aid-in-dying. The vast majority of people who raise the possibility of assisted dying with their doctor will not go on to make a formal request. When healthcare professionals can respond openly to such requests for a peaceful death, the likelihood of successfully addressing fears or reasons behind the request is much greater than when people are deterred by the law from expressing their concerns and wishes²⁹.

Assisted dying in Oregon has not changed in 20 years

The assisted dying law in Oregon has remained unchanged for 20 years. Attempts to change the law, for instance to extend the criteria on prognosis, have been steadfastly opposed by supporters of the assisted dying law and by patient groups³⁰.

The assisted dying law is only for dying people of sound mind —these criteria, and the safeguards associated with them, have not broadened since the law was enacted. Fears of a “slippery slope” have proved to be unfounded.

The law sets out strict eligibility criteria

The option of an assisted death is only available to people who are terminally ill. This is clearly evidenced in Oregon’s Death with Dignity Act Annual Report, which states that 77.9% of people using the Act since 1998 had cancer and 7.8% suffered from amyotrophic lateral sclerosis often referred to as motor neurone disease, or MND, in the UK. In addition, respiratory disease, heart disease, HIV, liver disease and other neurological diseases such as Parkinson’s are listed as underlying illnesses in the report. Chronic diseases that have been managed successfully for many years can enter a terminal phase eventually. At this point if the person is likely to die within six months, with or without treatment, they may become eligible for assisted dying in Oregon. Fears of extending the law to people who are not dying have not been realised.

**THE LAW
WORKS AS
INTENDED**

**FEARS IT WOULD
BE EXTENDED HAVE
NOT BEEN REALISED**

The law protects individual autonomy and dignity at the end of life

The availability of the option of assisted dying gives terminally ill people choice at the end of life which is the overwhelming motivational factor behind the decision to request assistance to die³¹.

“On the day he died, he was still able to communicate and say goodbye. It would have been so much more traumatic to see him waste away. Rick wasn’t afraid of pain or being a burden to us. He just wanted to be in control.”³²

Nora Miller, whose husband Rick had an assisted death

Upfront safeguards protect the public, prevent coercion and value individual choice

Studies of the law in Oregon demonstrate it is safe and effective. Concerns the law could be disproportionately used by people who are disabled, elderly, frail, uninsured or vulnerable have not materialised³³.

People from groups that might be considered vulnerable are proportionately less likely to use medical aid-in-dying. The law is only for dying people of sound mind.

Coercion of vulnerable people was a far greater risk prior to the implementation of a transparent system with safeguards and effective regulation.

DISABILITY RIGHTS OREGON, AN ORGANISATION COMMITTED TO PROTECTING OREGONIANS LIVING WITH DISABILITIES, HAS NEVER RECEIVED A COMPLAINT OF ABUSE OR ATTEMPTED ABUSE UNDER THE OREGON DEATH WITH DIGNITY ACT.³⁴

Safeguards ensure that a person's capacity to make healthcare decisions is well established

A level of sadness is normal for dying people³⁵. Research from Oregon using an inclusive approach to diagnosing depression (i.e. attributing physical symptoms such as sleeplessness, weight loss, fatigue and lack of appetite to depression) found that most people who request medical aid-in-dying do not have a depressive disorder. The authors acknowledged that among the few people in their study who used the law whilst having potential symptoms of depression, there was no evidence that they did not have capacity³⁶. Indeed all of the symptoms used for this definition are common effects of terminal diseases.

It has also been shown that when physicians suspect that a psychological disorder is impairing judgment, they decline the request rather than refer the person for a psychiatric evaluation³⁷.

Doctor participation in the law is strictly voluntary

The law allows health care professionals to choose whether to participate in any aspect of the Death with Dignity Act. While most people are able to stay with their existing medical team or healthcare system when going through the process, if a doctor is unwilling to honour a person's request, the person may transfer their care to a new provider. In this context, it is important to note that many Catholic hospitals refuse to participate in assisted dying⁴⁰, and that for those living in rural areas of Oregon, there may be no providers within 100 miles willing or able to dispense the necessary drugs⁴¹. This obliges people to seek support outside of their immediate locality. Opponents of assisted dying legislation often refer to this process using the scare language of "doctor shopping" but this is not an accurate description.

A healthcare professional's willingness to participate in the law does not mean that their patients will be exempt from adhering to the safeguards. If a patient changes healthcare systems in order to access medical aid-in-dying they must re-establish their entire care and request for assisted dying with the new medical team.

END-OF-LIFE CARE HAS FLOURISHED

WITH DOCTORS IMPROVING THEIR SKILLS IN DIAGNOSING DEPRESSION, MANAGING PAIN AND REFERRING PEOPLE FOR HOSPICE CARE. ^{38,39}

There are oversight and investigation processes in place to ensure correct implementation of the law

Assisted dying is thoroughly monitored and controlled by stringent eligibility and qualification processes, mandatory state reporting by the medical team, as well as medical board oversight and justice department investigatory power when appropriate. This scrutiny has contributed to the safe implementation of the law.

ASSISTED DYING IS THOROUGHLY MONITORED

AND CONTROLLED BY STRINGENT ELIGIBILITY AND QUALIFICATION PROCESSES.

The Oregon model has enabled millions of Americans, Canadians and Australians to have greater choice at the end of life

Following the successful implementation of the assisted dying law in Oregon, California, Colorado, the District of Columbia, Montana, Vermont and Washington have all given mentally competent, terminally ill adults the option of a legal assisted death⁴².

The experience in Oregon informed Canada's medical assistance in dying law and was also incorporated into the assisted dying legislation in Victoria, Australia, which was passed in November 2017.

Notes

- 1 Cover page quote: Willamette Week, The True Story of How Oregonians Won the Bitter Battle for the Right to Die, 1 November 2017 <http://www.week.com/news/state/2017/10/31/how-oregonians-won-the-bitter-battle-for-the-right-to-die/>
 - 2 While the terminology used is different in the United States and in the UK (medical aid-in-dying and assisted dying respectively), the principles are the same in that it allows terminally ill adults to control the manner and timing of their death through the voluntary self-administration of life-ending medication, expressly prescribed by a physician for that purpose subject to a range of safeguards
 - 3 Death with Dignity Act 1997 - <http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Pages/index.aspx>
 - 4 Oregon Death with Dignity Act, Data Summary 2017 (February 2018) <http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year20.pdf>
 - 5 Battin MP, van der Heide A, Ganzini L, van der Wal G and Onwuteaka-Philipsen BD (2007) Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in 'vulnerable' groups *Journal of Medical Ethics* 33: 591-97
 - 6 Ganzini L, Beer TM, Brouns M et al (2006) Interest in physician-assisted suicide among Oregon cancer patients *Journal of Clinical Ethics* 17: 27-38
 - 7 Oregon Death with Dignity Act, Data Summary 2017 (February 2018)
 - 8 L. Ganzini et al., (2002) "Experiences of Oregon nurses and social workers with hospice patients who requested assistance with suicide," *New England Journal of Medicine* 347: 582-8;
 - 9 Barbara Roberts, former Oregon governor, *Supra* note 1
 - 10 Majority of Americans Remain Supportive of Euthanasia Gallup, June 2017, <http://www.gallup.com/poll/211928/majority-americans-remain-supportive-euthanasia.aspx>
 - 11 Ron Wyden, former Oregon congressman and U.S. senator, *Supra* note 1
 - 12 Oregon Death with Dignity Act, Data Summary 2017 (February 2018)
 - 13 Position adopted by OHPCA Board of Directors April 21, 2017 - <https://oregonhospice.org/hospice-and-dwd/>
 - 14 Healthcare Professional Associations Recognize Medical Aid in Dying, Compassion and Choices 2016 - <https://www.compassionandchoices.org/wp-content/uploads/2016/07/FS-Medical-Aid-in-Dying-Healthcare-Professional-Orgs-FINAL-11.1.16-Approved-for-Public-Distribution.pdf> also lists other organisations that are supportive or neutral on the issue of assisted dying.
 - 15 Oregon Nurses Association, 1997 and 2015
 - 16 American Public Health Association, Patients' Rights to Self-Determination at the End of Life 2008, <https://www.apha.org/policies-and-advocacy/public-health-policy-statements/policy-database/2014/07/29/13/28/patients-rights-to-self-determination-at-the-end-of-life>
 - 17 Physician-Assisted Death: Where Do You Stand? January, 2017 www.medscape.com/viewarticle/874341
 - 18 California Pacific Conference 2015, End-of-life Options, Resolution 15-12 <http://www.calpacumc.org/wp-content/uploads/2015/01/Section-7.pdf>
 - 19 Rodney Page, *Supra* note 1
 - 20 Compassion and Choices, Board of Advisors <https://www.compassionandchoices.org/who-we-are/>
- Faith Community Resources available at <https://www.compassionandchoices.org/communities/faith-communities-for-choices/faith-resources/>
- 21 Centre to Advance Palliative Care, State-By-State Report Card on Access to Palliative Care, (2013), <https://reportcard.ccapc.org/>
 - 22 Wang Shi-Yi, Aldridge M D, Gross CP, Canavan M, Cherlin E, Johnson-Hurtzler R, Bradley E (2015) Geographic Variation of Hospice Use: Patterns at the End of Life *Journal of Palliative Medicine*. September 18(9): 771-780
 - 23 Oregon Death with Dignity Act, Data Summary 2017 (February 2018)
 - 24 Quill TE (2007) Legal regulation of physician-assisted death—the latest report cards *New England Journal of Medicine* 356:1911-1913
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 - 26 Tolle SW, Tilden VR, Drach LL, et al (2004) Characteristics and proportion of dying Oregonians who personally consider physician-assisted suicide *Journal of Clinical Ethics* 15:111-118.
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 - 28 Oregon POLST Registry Annual Report 2016
 - 29 Compassion and Choices, Medical aid-in-dying improves care at the end of life, February 2016
 - 30 Oregon Live, 3 March 2015, http://www.oregonlive.com/mapes/index.ssf/2015/03/bill_to_expand_oregons_dying_w.html
 - 31 Compassion & Choices, Medical Aid in Dying Fact Sheet, 2017
 - 32 Nora Miller, whose husband used the law in 1999, *Supra* note 1
 - 33 Battin et al, (2007) *Supra* note 5
 - 34 Compassion and Choices, Medical Aid in Dying and People Living with Disabilities 2016, <https://www.compassionandchoices.org/wp-content/uploads/2016/02/FS-Medical-Aid-in-Dying-and-People-Living-With-Disabilities-FINAL-2.22.16-Approved-for-Public-Distribution.pdf>
 - 35 Ganzini L et al, (2003) If it isn't depression... *Journal of Palliative Medicine* 6(9): 927-931
 - 36 Ganzini, L., E.R. Goy & S.K. Dobscha (2008) Prevalence of depression and anxiety in patients requesting physicians' aid in dying: cross sectional survey. *BMJ* 337: a1682 <http://www.bmj.com/content/337/bmj.a1682>
 - 37 Coombs-Lee, B (2014) Oregon's experience with aid in dying: findings from the death with dignity laboratory *Ann. N.Y. Acad. Sci.* <https://socialwork.columbia.edu/wp-content/uploads/Aid-in-Dying-BCL-914-3-1.pdf>
 - 38 Ganzini, L, Nelson, HD, Schmidt, TA, Kraemer, DF, Delorin, MA, Lee, MA. (2000) Physicians' experiences with the Oregon death with dignity act. *New England Journal of Medicine.* 342: 558
 - 39 Tolle SW et al. (2017) Lessons from Oregon in Embracing Compassion in End-of-Life Care, *N Engl J Med* 2017; 376:1078-1082
 - 40 Kathrine Stewart, At Catholic Hospitals, a 'Right to Life' but Not a Right to Death, *The Nation*, October 2015 <https://www.thenation.com/article/at-catholic-hospitals-a-right-to-life-but-not-a-right-to-death/>
 - 41 Jonel Aleccia, Legalizing Aid In Dying Doesn't Mean Patients Have Access To It, NPR January 2017, <https://www.npr.org/sections/healthshots/2017/01/25/511456109/legalizing-aid-in-dying-doesnt-mean-patients-have-access-to-it>
 - 42 For a summary of the laws in the United States see Compassion & Choices Near You - <https://www.compassionandchoices.org/near-you/>

CAMPAIGN FOR DIGNITY IN DYING.

We believe that everybody has the right to a good death, including the option of assisted dying for terminally ill, mentally competent adults.

Find out more and get involved at
www.dignityindying.org.uk

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