

# History of the End-of-Life Choice Movement

## 1967

A right-to-die bill is introduced in the Florida Legislature, arousing extensive debate, but ultimately is unsuccessful.

## 1971

Hospice, Inc. was founded in the United States.

## 1980

The Hemlock Society, an end-of-life care organization for those suffering with incurable illnesses, forms. It later evolves into End-of-Life Choices, which in 2005 merges with Compassion in Dying to form Compassion & Choices, the largest organization in the United States advocating for people's rights at the end of life.

## 1990

The U.S. Supreme Court rules in *Cruzan v. Director, Missouri Department of Health*, affirming the right of Americans to refuse unwanted medical treatment and their right to appoint a healthcare proxy to speak for them when they cannot.<sup>1</sup>

## 1994

Compassion in Dying develops and files two federal lawsuits — *Glucksberg v. Washington*<sup>2</sup>

<sup>1</sup> *Cruzan v. Director, Missouri Department of Health*, 497 U.S. 261 (1990) Available from [https://scholar.google.com/scholar\\_case?case=8467471114673973761&hl=en&as\\_sdt=6&as\\_vis=1&oi=scholar](https://scholar.google.com/scholar_case?case=8467471114673973761&hl=en&as_sdt=6&as_vis=1&oi=scholar)

<sup>2</sup> *Washington v. Glucksberg*, 850 F.Supp. 1454 (1994) Available from

Compassion & Choices is the leading nonprofit organization working to improve care, expand options and empower everyone to chart their end-of-life journey. For more than 30 years we have worked to change attitudes, practices and policies so that everyone can access the information and options they need to have more control and comfort at the end of life.

and *Quill v. NY*<sup>3</sup> — asserting that a mentally capable, terminally ill patient has a right protected by the constitutional guarantees of liberty, privacy and equal protection to choose aid in dying. The Federal District Court for the Western District of Washington rules that this right exists. The state of Washington appeals the decision to the Ninth Circuit Court of Appeals.

Oregon voters approve the Oregon Death With Dignity Act, a ballot initiative that permits terminally ill patients, under specified standards, to obtain a physician's prescription to shorten the dying process in a humane and dignified manner. The measure passed with 51% of the vote.<sup>4</sup>

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<sup>3</sup> *Quill v. NY*, 870 F.Supp. 78 (1994) Available from [https://scholar.google.com/scholar\\_case?case=3517468751551118375&hl=en&as\\_sdt=6,38](https://scholar.google.com/scholar_case?case=3517468751551118375&hl=en&as_sdt=6,38)

<sup>4</sup> Department of Human Resources Oregon Health Division Center for Disease Prevention and Epidemiology.

## 1996

The Ninth Circuit Court of Appeals (in *Glucksberg v. Washington*)<sup>5</sup> and the Second Circuit Court of Appeals (in *Quill v. NY*)<sup>6</sup> both decide that the U.S. Constitution protects the choice of a capable, terminally ill patient to choose aid in dying. The states of New York and Washington appeal the decision in the U.S. Supreme Court.

## 1997

The National Right-to-Life Committee challenges Oregon's Death With Dignity Act, stalling implementation until the challenge is dismissed by the Ninth Circuit Court of Appeals. The Oregon Legislature puts a measure on the ballot to rescind the law, but it is defeated by 60% of the voters. Later that year, Compassion in Dying client "Helen" becomes the first person to use the law to die peacefully.

In *Glucksberg v. Washington*<sup>7</sup> and *Attorney General Vacco of New York v. Quill*<sup>8</sup>, the U.S. Supreme Court declines to find federal constitutional protection for medical aid in dying and refers the issue to the states.

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*Oregon's Death with Dignity Act: The First Year's Experience*. February 18, 1999. Available from <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year1.pdf>

<sup>5</sup> *Compassion in Dying v. Washington*, 79 F.3d 790 (1996) Available from [https://scholar.google.com/scholar\\_case?case=16022278741236628449&hl=en&as\\_sdt=6,38](https://scholar.google.com/scholar_case?case=16022278741236628449&hl=en&as_sdt=6,38)

<sup>6</sup> *Quill v. NY*, 80 F.3d 716 (1996) Available from [https://scholar.google.com/scholar\\_case?case=524258359137515638&hl=en&as\\_sdt=5,38&scioldt=6,38](https://scholar.google.com/scholar_case?case=524258359137515638&hl=en&as_sdt=5,38&scioldt=6,38)

<sup>7</sup> *Washington v. Glucksberg*, 521 US 702 (1997) Available from [https://scholar.google.com/scholar\\_case?case=17920279791882194984&hl=en&as\\_sdt=6&as\\_vis=1&oi=scholar](https://scholar.google.com/scholar_case?case=17920279791882194984&hl=en&as_sdt=6&as_vis=1&oi=scholar)

<sup>8</sup> *Vacco v. Quill*, 521 U.S. 793 (1997) Available from [https://scholar.google.com/scholar\\_case?case=10644975876581235704&hl=en&as\\_sdt=6,38](https://scholar.google.com/scholar_case?case=10644975876581235704&hl=en&as_sdt=6,38)

However, the court recognizes a federal constitutional right for dying patients to receive as much pain medication as necessary to obtain relief, even if this advances the time of death.

## 2001

Compassion & Choices represents the Bergman family of California in bringing the nation's first case to claim that failure to treat pain adequately constitutes elder abuse, winning a \$1.5M verdict for patients' pain and suffering. The case establishes that failure to treat pain adequately can result in significant financial risk to healthcare providers.<sup>9</sup>

## 2002

Attorney General John Ashcroft issued a directive in 2001 to prevent the Oregon Death With Dignity Act from being implemented. The state of Oregon sued to stop the directive, joined by a group of terminally ill Oregonians and represented by Compassion & Choices. Federal District Court Judge Robert E. Jones in *Oregon v. Ashcroft*<sup>10</sup> rules against the Ashcroft directive rebuking the federal government for its attempt to "stifle an ongoing, earnest and profound debate in the various states" concerning aid in dying.

## 2004

The state of Oregon asks the United States Ninth Circuit Court of Appeals in *Oregon v. Ashcroft* to affirm the lower court decision,

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<sup>9</sup> Rich, Ben A., *Physicians' legal duty to relieve suffering*. West J Med. 2001 Sep; 175(3): 151–152. Available from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1071521/>

<sup>10</sup> *Oregon v. Ashcroft*, 192 F. Supp. 2d 1077 (2002) Available from [http://scholar.google.com/scholar\\_case?case=17507293978677110948&hl=en&as\\_sdt=6&as\\_vis=1&oi=scholar](http://scholar.google.com/scholar_case?case=17507293978677110948&hl=en&as_sdt=6&as_vis=1&oi=scholar)

which it does, leaving the Oregon Death With Dignity Act intact.<sup>11</sup>

## 2006

Medical associations begin to adopt policies that support aid in dying, including The American Women's Medical Association, the American Public Health Association and The American Medical Students' Association.

## 2008

On November 4, Washington state voters overwhelmingly approve by ballot measure the Death With Dignity Act by a margin of 59% to 41%. Washington becomes the second state to authorize medical aid in dying.<sup>12</sup>

In December, Montana District Court Judge Dorothy McCarter holds that the Montana Constitution protects a peaceful death with dignity, making Montana the third state to authorize medical aid in dying.<sup>13</sup>

## 2009

On December 31, the Montana Supreme Court rules in favor of the landmark case brought by Compassion & Choices (*Baxter v. Montana*), affirming that it is not against Montana public policy for a physician to provide medical aid in dying to a mentally capable, terminally ill individual.<sup>14</sup>

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<sup>11</sup> *Oregon v.s Ashcoft*, 368 F.3d 1118 (2004) Available from [https://scholar.google.com/scholar\\_case?case=6864220915455147792&hl=en&as\\_sdt=6,38](https://scholar.google.com/scholar_case?case=6864220915455147792&hl=en&as_sdt=6,38)

<sup>12</sup> Washington Death With Dignity Act. Complete Chapter 70.245 RCW. Enacted November 2008. Available from [http://www.wsha.org/wp-content/uploads/Death-with-Dignity\\_i1000-text.pdf](http://www.wsha.org/wp-content/uploads/Death-with-Dignity_i1000-text.pdf)

<sup>13</sup> *Baxter v Montana*. District Court Ruling Available from <https://www.compassionandchoices.org/wp-content/uploads/2016/02/Judge-Dorothy-McCarters-Decision.pdf>

<sup>14</sup> *Baxter v. Montana*. Supreme Court of Montana, 224 P.3d 1211 (2009). Available from

## 2010

New York passes the Palliative Care Information Act (PCIA) in August. The law, drafted by Compassion & Choices and modeled after a similar measure in California, requires healthcare workers to provide information and counseling on end-of-life options.<sup>15</sup>

## 2011

The U.S. Conference of Catholic Bishops (USCCB) issues its first official statement condemning aid in dying. Compassion & Choices responds by holding a press conference on the same day, in the same building, refuting the USCCB's false claims throughout national media.<sup>16</sup>

Award-winning documentary about Oregon's Death With Dignity Act, *How to Die in Oregon*, is released, featuring Compassion & Choices volunteers and clients.<sup>17</sup>

## 2012

Compassion & Choices becomes a member of the Leadership Conference on Civil and Human Rights, the nation's premier coalition promoting and protecting civil and human rights in the United States.

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<sup>15</sup> New York State Assembly. New York Public Health Law § 2997-c. Palliative care patient information. Available from

[http://assembly.state.ny.us/leg/?default\\_fld=&bn=A07617&term=2009&Text=Y](http://assembly.state.ny.us/leg/?default_fld=&bn=A07617&term=2009&Text=Y)

<sup>16</sup> Compassion & Choices media release, June 16, 2011. Available from

<https://drive.google.com/file/d/0B3luDjCAxxv7NUdvWDlFNFE2LUc1bDRDUHN5UHNkSzJRMek0/view?usp=sharing>

<sup>17</sup> *How to Die in Oregon* website. Available from <http://www.howtodieinoregon.com/>

## 2013

On May 20, Vermont becomes the fourth state to authorize aid in dying and the first in the nation to do so through the legislature.<sup>18</sup>

In December, Compassion & Choices joins with aging-focused organizations, healthcare-reform groups and legal experts to launch the Campaign to End Unwanted Medical Treatment.<sup>19</sup>

## 2014

On January 14, medical aid in dying is authorized in New Mexico due to a lawsuit filed jointly by Compassion & Choices and the American Civil Liberties Union. In her ruling, the presiding judge writes, "This court cannot envision a right more fundamental, more private or more integral to the liberty, safety and happiness of a New Mexican than the right of a competent, terminally ill patient to choose aid in dying."<sup>20</sup>

Compassion & Choices releases a national poll showing that 25 million people per year experience unwanted medical treatment.<sup>21</sup>

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<sup>18</sup> Vermont Patient Choice and Control at the End of Life Act. Act 039, Chapter 113. Enacted May 2013. Available from

<http://www.leg.state.vt.us/docs/2014/Acts/ACT039.pdf>

<sup>19</sup> Powerful Coalition Forms to Advance the Campaign to End Unwanted Medical Treatment. December 12, 2013. Available from

<https://drive.google.com/a/compassionandchoices.org/file/d/0B3luDjCaxxv7azR5S3B4UkFDvVk/view?usp=sharing>

<sup>20</sup> *Morris v. Brandenburg*, D-202-CV-2012-02909 (2014).

<https://drive.google.com/file/d/0B2J2qeQEZsj0cmhGcW1vZEIly2s/view?usp=sharing>

<sup>21</sup> 25 Million Older Americans Have Experienced Unwanted or Excessive Medical Treatment, Survey Suggests. July 29, 2014 Available from

<https://www.compassionandchoices.org/25-million-older-americans-have-experienced-unwanted-or-excessive-medical-treatment-survey-suggests/>

A Pennsylvania judge dismisses all charges against Barbara Mancini, a nurse who was arrested for handing her dying father his prescription morphine. The Pennsylvania Attorney General charged Barbara Mancini for assisting the death of her 93-year-old terminally ill father, whom Barbara was caring for while he was on home hospice care. Compassion & Choices ignites a nationwide discussion on end-of-life autonomy through its campaign to have the charges dropped.<sup>22</sup>

The National Academy of Medicine (formerly Institute of Medicine) releases "Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life." Compassion & Choices conducted educational briefings and commissioned policy papers in support of the report's recommendations.<sup>23</sup>

Brittany Maynard, a terminally ill 29-year-old Californian, releases a video as part of a transformative joint campaign with Compassion & Choices to expand access to medical aid in dying in California and nationwide. The video garners 9 million views in its first three weeks on YouTube, and coverage from every major news outlet catalyzes not only a nationwide conversation on death with dignity but more than two dozen aid-in-dying bills introduced in state legislatures around the country.<sup>24</sup>

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<sup>22</sup> Judge Dismisses Assisted Suicide Case Against Pennsylvania Nurse. Feb. 12, 2014. Available from <http://www.npr.org/sections/healthshots/2014/02/12/275913772/judge-dismisses-assisted-suicidcase-against-pennsylvania-nurse>

<sup>23</sup> Institute of Medicine Report on Dying in U.S. Praised by End-of-Life Choice Organization. Sept. 17, 2014.

Available from <https://www.compassionandchoices.org/institute-of-medicine-report-on-dying-in-u-s-praised-by-end-of-life-choice-organization/>

<sup>24</sup> Brittany Maynard Family, Compassion & Choices Making End-of-Life Care Progress, March 10, 2015. Available from

## 2015

Twenty-five state legislatures and the District of Columbia introduce medical aid-in-dying bills.<sup>25</sup>

U.S. Senators Mark Warner (D-VA) and Johnny Isakson (R-GA) introduce the bipartisan Care Planning Act of 2015, which would create a Medicare benefit for people facing grave illness to work with their doctor to document their personal goals for treatment. Compassion & Choices endorsed this legislation.<sup>26</sup>

The California Medical Association drops its 28-year opposition to medical aid in dying by taking a neutral position on the End of Life Option Act.<sup>27</sup>

The New Mexico Court of Appeals issues a decision on Aug 11, 2015, finding that there is no fundamental right to aid in dying in New Mexico, reversing the decision of District Judge Nash's 2014 ruling.<sup>28</sup>

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<https://www.compassionandchoices.org/brittany-maynard-family-compassion-choices-making-end-of-life-care-progress/>

<sup>25</sup> Compassion & Choices Celebrates Day of Gratitude in Honor of Brittany Maynard's Birthday. Nov. 19, 2015. Available from

<https://www.compassionandchoices.org/compassion-choices-celebrates-day-of-gratitude-in-honor-of-brittany-maynards-birthday/>

<sup>26</sup> Warner, Isakson Introduce Bipartisan Bill to Improve Planning Options for Patients with Advanced Illness. June 10, 2015 Available from

<http://www.warner.senate.gov/public/index.cfm/2015/6/warner-isakson-introduce-bipartisan-bill-to-improve-planning-options-for-patients-with-advanced-illness>

<sup>27</sup> California Medical Association removes opposition to physician aid-in-dying bill. May 20, 2015. Available from <http://www.cmanet.org/news/press-detail/?article=california-medical-association-removes>

<sup>28</sup> *Morris v. Brandenburg*, 33,630 (N.M. Ct. App. 2015) Available from

<https://www.aclu-nm.org/sites/default/files/wp-content/uploads/2015/08/Morris-Writ-endorsed-no-signature-08-19-15.pdf>

California becomes the fifth state to authorize medical aid in dying by passing the End of Life Option Act and thereby providing a total of 16% percent of the U.S. population access to the full range of end-of-life care options.<sup>29</sup>

The Centers for Medicare & Medicaid Services issues a rule to reimburse doctors for advance planning and end-of-life conversations after successful advocacy by Compassion & Choices and other aging and healthcare organizations.<sup>30</sup>

## 2016

Colorado becomes the sixth state to authorize medical aid in dying by passing the End-of-Life Options Act, thereby increasing the total of the U.S. population with access to the full-range of end-of-life care options to 18%.<sup>31</sup>

The District of Columbia became the seventh jurisdiction in the U.S. where medical aid in dying is authorized after the D.C Council passed the D.C. Death with Dignity Act by a veto-proof 11-2 margin on November 15, 2016, and signing of the bill by Mayor Muriel Bowser on December 20, 2016.<sup>32</sup> Compassion & Choices led the effort to block congressional interference and an attempt to overturn the bill shortly after its passage.

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<sup>29</sup> California End of Life Option Act. ABX2-15 End of life. Enacted October 2015. Available from [http://leginfo.legislature.ca.gov/faces/billTextClient.xhtml?bill\\_id=201520162AB15](http://leginfo.legislature.ca.gov/faces/billTextClient.xhtml?bill_id=201520162AB15)

<sup>30</sup> CMS Allows Reimbursement for Advance Planning. November 6, 2015. Available from <https://www.compassionandchoices.org/cms-allows-reimbursement-for-advance-planning/>

<sup>31</sup> Colorado End-of-Life Options Act, Proposition 106, Passed November 8, 2016, Pending implementation. Available from <http://coendoflifeoptions.org/wp-content/uploads/2016/06/Full-Text-of-Measure.pdf>

<sup>32</sup> District of Columbia's Death with Dignity Act of 2015, Available from <http://lims.dccouncil.us/Legislation/B21-0038?FromSearchResults=true>

## 2017

Compassion & Choices merged with DeathWise, a nonprofit that helps people plan for the end of their lives with interactive online tools and resources.

In Congress, C&C achieved its first federal win in a decade by staving off a Resolution of Disapproval to nullify D.C.'s medical aid-in-dying law, then successfully mobilized thousands of supporters to call on representatives to reject a matching amendment passed by the House Appropriations Committee.

The Massachusetts Medical Society dropped its opposition to medical aid in dying legislation, adopting a stance of "engaged neutrality" allowing their members to access education, advocacy and other resources on aid in dying.<sup>33</sup>

Compassion & Choices launched African-American and Latino Leadership Councils, an extension of its successful outreach to communities of color that was key to winning campaigns to pass laws authorizing medical aid in dying in California in 2015, and Colorado and the District of Columbia in 2016.

## 2018

Hawai'i became the eighth jurisdiction in the U.S. to authorize medical aid in dying when

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<sup>33</sup> Massachusetts Medical Society adopts several organizational policies at Interim Meeting December 2, 2017 Available from: <http://www.massmed.org/News-and-Publications/MMS-News-Releases/Massachusetts-Medical-Society-adopts-several-organizational-policies-at-Interim-Meeting/#.Wk1FybT83BJ>

Governor David Ige signed the Our Care, Our Choice Act into law on April 5, 2018.<sup>34</sup>

More than 2,400 people acted on our email request to submit comments on proposed federal regulations that would empower a division of the U.S. Department of Health and Human Services to facilitate physicians' ability to impose religious beliefs on their patients by denying information and access to lawful end-of-life care options.

The American Medical Association rejected its Council on Ethical and Judicial Affairs' recommendation to reaffirm the organization's longtime opposition.

In California, a Riverside County judge ruled to invalidate the California End of Life Option Act. Compassion & Choices filed a motion with the judge to vacate the decision. When he rejected that motion, Compassion & Choices filed a notice of appeal with the appellate court which resulted in the law's reinstatement.

The American Academy of Family Physicians adopted a policy of "engaged neutrality" toward medical aid in dying and rejected the term "assisted suicide."

## 2019

New Jersey became the ninth jurisdiction in the U.S. to authorize medical aid in dying when Governor Phil Murphy signed the Medical Aid in Dying for the Terminally Ill Act into law on April 12, 2019. Maine became the tenth jurisdiction to authorize medical aid in dying when Governor Janet Mills signed the Death with Dignity Act into law on June 12, 2019.

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<sup>34</sup> HB2739 Our Care, Our Choice Act, Available from: <https://www.capitol.hawaii.gov/session2018/bills/HB2739.HTM>

Compassion & Choices Founder, President Emerita and Senior Adviser Barbara Coombs Lee publishes her second book, *Finish Strong: Putting Your Priorities First at Life's End*, about transforming the end-of-life experience through education and empowerment.

## 2020

In response to myriad challenges brought on by the coronavirus pandemic, Compassion & Choices developed a free comprehensive COVID-19 Toolkit in both English and Spanish; launched a virtual *Staying Stronger Together* webinar series addressing an array of topics including end-of-life planning, virtual advocacy and medical aid in dying; and helped secure critical provisions in the Coronavirus Aid, Relief and Economic Security (CARES) Act, including improvements to telehealth laws, ensuring safe and equitable access to care for terminally ill patients without the health risks of in-person visits.

In September, Compassion & Choices launched a nationwide campaign to help people prepare in advance for a dementia diagnosis, including our free online dementia planning tools — the Dementia Values and Priorities Tool and the Dementia Decoder — and two new videos about the tools. This issue was especially timely because new scientific research indicated a rise of dementia in response to the COVID-19 pandemic.

## 2021

After 24 years of effort, New Mexico became the 11th jurisdiction to pass a medical aid-in-dying law with Governor Michelle Lujan Grisham's signing on April 9. New Mexico's law

featured a number of provisions that make it more accessible than prior states':

- Allows advanced practice registered nurses and physician assistants to support their patients by serving as either the prescribing or consulting clinician.
- Streamlines the waiting period for receiving aid-in-dying medication to 48 hours and provides the prescribing provider with the ability to waive it if a person is likely to die before the waiting period expires.
- Clarifies that if a healthcare provider objects to participating in medical aid in dying that they must inform the patient and refer them to either a healthcare provider who is able and willing to carry out the request or to another person or entity to assist them.