

Our Accomplishments: Improving Care and Expanding Options for the End of Life

For more than 30 years, by using a comprehensive strategy including legislative advocacy, grassroots organizing, media outreach and litigation, Compassion & Choices and our predecessor organizations have led most of the significant advances in the movement to expand end-of-life-options and improve care. This includes:

Advance Care Planning and End-of-Life Support

Compassion & Choices is the leading advocate for making important healthcare plans in advance and developing patient-centered end-of-life care tools:

- Developed the first national end-of-life consultancy program in 1993, which offers patients and their families tools, information and emotional support on the full range of available end-of-life options.
- Pioneered the use of and transformed advance directives from strictly legal documents to a values-based approach for communicating end-of-life priorities.
- Developed a dementia provision, and created one of the early and most widely disseminated toolkits to help translate people's values into care preferences.

- Advocated for the successful adoption of a new Centers for Medicare and Medicaid Services rule allowing the agency to reimburse doctors for advance healthcare planning discussions.

Palliative Care and Pain Management

Compassion & Choices stands at the forefront of championing patient rights and appropriate care at the end-of-life:

- Legitimized palliative sedation as a recognized medical practice by advancing the court case that recognized dying patients have a constitutional right to receive as much pain medication as necessary, even if it advances the time of death, in the U.S. Supreme Court decision *Vacco v. Quill* (1997).
- Established the undertreatment of pain as a form of elder abuse and that caregivers must manage patients' pain in *Bergman v. Eden Medical Center* (2001).
- Increased physician training in palliative care in California. Passed AB 487: Pain Management and the Appropriate Care and Treatment of the Terminally Ill in California in 2001, collaborating with the California Medical Association. The law requires most California-licensed physicians to take, as a one-time requirement, 12 units of continuing

medical education on pain management and “the appropriate care and treatment of the terminally ill.”

- Enacted requirements that healthcare providers share information on end-of-life options. Compassion & Choices sponsored and helped pass the Palliative Care Information Act in New York (2010) that requires healthcare workers to provide information and counseling on end-of-life options and the Right to Know law in California designed to ensure that patients can receive information about all of their legal end-of-life options.

Medical Aid in Dying

Compassion & Choices is the oldest and largest organization in the movement to expand end-of-life-options and improve care at the end of life:

- Compassion & Choices President Barbara Coombs Lee co-authored Oregon’s landmark Death With Dignity Act, which went into effect in 1997. Twenty years later, lawmakers continue to look at the Oregon experience and are developing new legislative approaches to medical aid in dying nationwide.
- Pioneered the model of medical aid in dying that helps ensure doctors can ethically practice in an open, legitimate and accessible way, and integrates the option into patients’ end-of-life care. The culmination of that work was the publication of clinical criteria in the *Journal of Palliative Medicine* in December 2015.
- Advanced *Glucksberg v. Washington* (1997) to the U.S. Supreme Court. The landmark ruling encouraged individual states to engage in an “earnest and profound debate about the morality,

legality and practicality of” medical aid in dying, setting the stage for the consideration of legislation at the state level.

- Medical aid in dying is authorized in ten jurisdictions: Oregon (1994, ballot initiative), Washington (2008, ballot initiative), Montana (2009, state Supreme Court decision), Vermont (2013, legislation), California (2015, legislation), Colorado (2016, ballot initiative), Washington, D.C. (2017, legislation), Hawai’i (2018, legislation), New Jersey (2019, legislation) and Maine (2019, legislation). Compassion & Choices is dedicated to the authorization and implementation of expanded end-of-life options.
- Protected the Oregon Death With Dignity Act in court against two challenges, one from the National Right to Life Group and one from the U.S. Attorney General; protected the authorization of medical aid in dying in Montana against five legislative attempts to overturn the law; and have protected the law in Vermont against repeated legislative attempts to repeal or weaken the law.

To learn more about the history of the end-of-life choice movement, please visit our website at CompassionAndChoices.org/resource/history-end-life-choice-movement/. While much has been accomplished, Compassion & Choices will continue our work until the full scope of end-of-life options are available to all Americans.