Federal Policy Agenda / 2016 & Beyond
Compassion & Choices is the leading national non-profit organization dedicated to improving care and expanding choice for people with advanced illness, and nearing or at the end of life. We work to change attitudes, practices and policies so that everyone can access the information and options they need to have more control and comfort as life ends.

We offer free consultation, planning resources, referrals and guidance, and across the nation we work to protect and expand end-of-life options. We also advocate for policies at the federal level that will improve person-centered care for those with advanced illness and approaching death.

The Institute of Medicine’s (IOM) 2014 report *Dying in America* affirmed C&C’s more than thirty years of experience influencing the healthcare system to provide compassionate, high-quality end-of-life care that respects the dignity and choices of patients and their families. Our federal policy agenda calls on policymakers to improve end-of-life care through actions we have identified in the five broad policy areas discussed in the IOM report.
1. **Delivery of Person-Centered, Family-Oriented Care**

People living with advanced illness or nearing the end of life need comprehensive, integrated care that provides meaningful information regarding care options, supports the expression of values and priorities, and ensures they guide decisions regarding tests and treatment as diseases advance. The IOM rightly states that we must promote policies that empower individuals to participate actively in their healthcare decision-making throughout their lives and as they approach death. This includes ensuring that clinicians seek patients’ preferences in decision-making, informing patients of all available treatment options including palliative care and making timely referrals to palliative care and hospice.

---

**Federal Policy Priorities**

- **Establish federal payment for palliative care consultations** provided by trained palliative care professionals who will advocate for and support the values and choices of the patient across settings for every person with an advanced illness or nearing the end of life.

- **Allow patients the option of enrolling in hospice** while still continuing to receive disease-specific and restorative treatments should they choose.

- **Ensure advanced illness care** encompasses access to an interdisciplinary care team including board-certified hospice and palliative medicine physicians, nurses, social workers, and with faith-based support together with other health professionals as needed.

- **Seek and promote policies** that hold providers accountable for recording and following a person’s wishes including a person’s right to decline services, and mandate public reporting of quality and cost measures.
Forthright and effective communication with healthcare professionals allows patients and their caregivers to understand the range of treatment options available, fully articulate values and priorities, and ultimately experience more positive encounters with the healthcare system; this is particularly important for those with advanced illness or nearing the end of life.

For these individuals, poor understanding of treatment options and/or lack of acknowledgment of the extent of the illness may lead to inadequate planning, dissatisfaction with the process, unnecessary medical treatment, loss of quality of life or reduced life. Patients and families (as appropriate) must be fully informed about all available treatment options including the benefits and drawbacks of each treatment option and what to expect as the illness progresses.

Finally, as patients and providers engage in comprehensive, in-depth conversations about their concerns and priorities, it is critical that these are carefully documented, recorded, and readily transferable across time and care or provider setting.

**Federal Policy Priorities**

Promote standardized quality measures that assess advanced illness care, including whether treatment was aligned with the patient's values and priorities as diseases advanced.

Require electronic medical records (EMR) to include advance care planning (ACP) information and the patient's values and priorities as diseases advance, and that the EMR be used for accountability measurement and payment decisions.

Provide federal funding and develop requirements in federal programs to ensure that healthcare professionals are trained to support the right of every patient facing an advanced illness or nearing the end of life, and to cover consultations by trained palliative care professionals from point of diagnosis.
3. **Professional Education and Development**

According to the IOM report, many physicians have a lack of training in communication skills, insufficient time, competing needs, and/or personal discomfort in discussing terminal prognoses and death.\(^1\) The current educational process for healthcare professions falls far short of ensuring competency in communication. A major undertaking is necessary to better prepare healthcare professionals for their role in providing care based on the values, priorities and preferences of the patient. There is inadequate focus on communication skills and the substance of advanced illness care and palliative care techniques in medical education.

---

**Federal Policy Priorities**

- **Bolster the professional and paraprofessional workforce** providing hospice, palliative and advance care services with the goal of ensuring that we train enough palliative care professionals to be able to provide consultation to every patient facing an advanced illness or nearing the end of their life. Such strategies may include recruitment, loan forgiveness, grants, competitive compensation, data collection and credentialing.

- **Push for a mandate** for nursing home and assisted-living education on ACP linked to reimbursement, and advocate for grants to facilities to train and certify direct-care workers in end-of-life care.

- **Request the Health Resources and Services Administration (HRSA) to include ACP training** in all its geriatric and other training programs.

- **Fund research** to measure the impact of interventions to promote ACP and patient-physician communication.
4. Policies and Payment Systems

The movement from a volume-based to a value-based health-care payment system is underway. Since the passage of the Affordable Care Act, the Centers for Medicare & Medicaid Services (CMS) has experimented with realigning incentives in the healthcare system in order to reward quality and outcomes while reducing costs. That said, the current fee-for-service approach to care delivery encourages perverse incentives that promote increased, unnecessary, uninformed and unwanted treatments, procedures and services offered in the hospital, ICU or emergency care settings. These siloed interventions also make it difficult to properly coordinate care across providers and settings. In order to promote accountability throughout the delivery system, it is critical to develop proper quality metrics to ensure that care is aligned with individual goals, values and wishes in accordance with the principle of person-centered care. In addition, hospice and care delivery structures should be re-engineered to move the focus of care to the individual’s home, and integrate long-term services and supports to help reduce hospitalizations and improve patient satisfaction.

Federal Policy Priorities

- **Encourage Congress to direct CMS and other federal agencies not to use appropriations or other funds to reimburse for treatment that was provided but unwanted, or where consent was given without knowledge of suitable palliative care options.**

- **Support the portability of ACP documents regardless of state law.**

- **Support the IOM’s recommendation to require the use of interpretable electronic health records that incorporate advance care planning to improve communication of individuals’ wishes across time, settings and providers; documenting (1) the designation of a surrogate/decision maker, (2) patient values and beliefs and goals for care, (3) the presence of an advance directive, and (4) the presence of medical orders for life-sustaining treatment for appropriate populations; and encourage states to develop and implement a Physician Orders for Life-Sustaining Treatment (POLST) paradigm program in accordance with nationally standardized core requirements.**
5. Public Education and Engagement

According to a survey conducted in 2011 by the California Healthcare Foundation, while the majority of survey participants (82 percent) noted that it was important to have end-of-life wishes in writing, only 23 percent of respondents said they had done so. A 2013 survey conducted by the Pew Research Center indicated that 22 percent of those aged 75 and older had neither written down nor talked to someone about their treatment preferences at the end of life. Building and fostering a continued public dialogue regarding end-of-life care issues is critical to helping individuals and their caregivers better cope and find more supports to guide them throughout the illness trajectory. There is much that can be accomplished at the societal level through federal policy in order to support the movement and continue driving momentum.

Federal Policy Priorities

Support education that promotes sanctions/penalties for those that administer unwanted medical treatment, including no payment for such treatment.

Advocate for HHS to coordinate the necessary research to issue a surgeon general's report, and develop and implement a national campaign to generate public awareness about the importance of having conversations with loved ones around values, priorities and wishes for the end of life.

Work for the creation of a commission and caucus to develop policies that ensure all people with advanced illness have access to skilled palliative care or, when appropriate, hospice care in all settings and related educational materials.
RESEARCH


<table>
<thead>
<tr>
<th>Year</th>
<th>National Polls</th>
<th>State Polls</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011</td>
<td>67% Support Aid in Dying</td>
<td>2011 HAWAII 71% Support Aid in Dying</td>
</tr>
<tr>
<td>2012</td>
<td>55% Support Aid in Dying</td>
<td>2012 VERMONT 74% Support Aid in Dying</td>
</tr>
<tr>
<td>2013</td>
<td>62% Support Right to Die</td>
<td>2012 NEW MEXICO 65% Support Aid in Dying</td>
</tr>
<tr>
<td>2014</td>
<td>74% Support Aid in Dying</td>
<td>2013 MONTANA 69% Support Aid in Dying</td>
</tr>
<tr>
<td>2015</td>
<td>68% Support Aid in Dying</td>
<td>2015 NEW JERSEY 63% Support Aid in Dying</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2015 MARYLAND 60% Support Aid in Dying</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2015 CONNECTICUT 63% Support Aid in Dying</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2015 CALIFORNIA 69% Support Aid in Dying</td>
</tr>
</tbody>
</table>
What Is Medical Aid in Dying?

Medical aid in dying is when a terminally ill, mentally capable person who has a prognosis of six months or less requests, obtains and—if their suffering becomes unbearable—self-administers medication that brings about a peaceful death.

Where Is Medical Aid in Dying Authorized?

Medical aid in dying is currently authorized in five states, either through statute or court decision: Oregon (1994, ballot initiative), Washington (2008, ballot initiative), Montana (2009, state Supreme Court decision), Vermont (2013, legislation) and most recently California (2015, legislation).

Why Is Medical Aid in Dying a Safe Practice?

Medical aid in dying is a safe and trusted medical practice because the eligibility requirements ensure that only mentally capable, terminally ill adults with a prognosis of six months or less who want the choice of a peaceful death are able to request and obtain aid-in-dying medication.

The states that authorized aid in dying through legislation modeled their bills after Oregon’s Death With Dignity Act. In those states, medical aid in dying is available to terminally ill adults who are mentally capable to make their own healthcare decisions, are free from undue influence and coercion, and have a prognosis of six months or less to live. Each state’s regulatory and procedural requirements are slightly different, but all the legislation includes the following provisions, among others:

- The patient must be fully informed of all their options
- The patient must request the prescription from a physician and be free from undue influence or coercion
- The patient must be able to self-administer the medication
- The physician must offer the patient multiple opportunities to rescind request for aid-in-dying medication
- Two witnesses need to sign the request form attesting to the voluntary nature of request
- Wills, contracts, insurance and annuity policies are unaffected by a person choosing aid in dying
- Aid in dying is not considered suicide or assisted suicide

How Well Has Medical Aid in Dying Worked in the States That Have Authorized It?

In the more than 30 combined years of medical aid in dying in the authorized states, there has not been a single instance of documented abuse. In Oregon, end-of-life care has improved overall since the law’s implementation, in large part due to the dialogue the Death With Dignity Act encourages between people and their doctors. Hospice referrals are up, as is the use of palliative care. Oregon now has the lowest rates of in-hospital deaths and the highest rates of at-home deaths in the nation, and violent suicide among hospice patients has virtually disappeared. Almost two decades of rigorously observed and documented experience in Oregon shows us the law has worked as intended, with none
of the problems opponents had predicted.

Where Does the American Public Stand on Medical Aid in Dying?

The American public consistently supports medical aid in dying by large majorities and is of great importance to voters, as measured by independent polling outlets such as Gallup (68 percent support in May 2015) and Harris (74 percent support in November 2014). State-by-state polling also indicates majority support that cuts across demographics.

Why Is It Wrong to Equate Medical Aid in Dying With Euthanasia?

Medical aid in dying is fundamentally different from euthanasia because in the act of euthanasia the physician – not the dying person – chooses and acts to cause the death of the patient. Compassion & Choices does not support euthanasia, which is illegal throughout the United States. With aid in dying, the patient must self-administer the medication and therefore always remains in control.

Which Organizations Support Medical Aid in Dying?

In addition to Compassion & Choices, national public health and medical organizations such as the American Public Health Association, American Medical Women’s Association and American Medical Student Association have adopted supportive positions on medical aid in dying at the national level. In California, the End of Life Option Act was endorsed by more than 75 organizations including the American Nurses Association/California, California Psychological Association and California Primary Care Association. The California Medical Association dropped its 28-year opposition to medical aid in dying and adopted a neutral position on the legislation, concluding: “As physicians, we want to provide the best care possible for our patients. However, despite the remarkable medical breakthroughs we’ve made and the world-class hospice or palliative care we can provide, it isn’t always enough … it’s up to the patient and their physician to choose the course of treatment best suited for the situation.”

Why Is It Wrong to Equate Medical Aid in Dying With Assisted Suicide?

Factually, legally and medically speaking, it is inaccurate to equate aid in dying with assisted suicide. People who consider aid in dying find the suggestion that they are committing suicide deeply offensive, stigmatizing and inaccurate. The Oregon, Washington, Vermont and California laws emphasize that: “Actions taken in accordance with [the Act] shall not, for any purpose, constitute suicide, assisted suicide, mercy killing or homicide, under the law.” This is because a person who is choosing medical aid in dying already has a terminal prognosis of six months or less to live. They are not choosing to die; the disease is taking their life. The terminally ill person who chooses aid in dying is simply choosing not to prolong a difficult and painful dying process.
Healthcare Professional Associations Recognize Medical Aid in Dying

The California Medical Association (CMA) 40,000+ members
Promotes the science and art of medicine, the care and well-being of patients, the protection of the public health and the betterment of the medical profession.

“As physicians, we want to provide the best care possible for our patients. However, despite the remarkable medical breakthroughs we’ve made and the world-class hospice or palliative care we can provide, it isn’t always enough. The decision to participate in the [California] End of Life Option Act is a very personal one between a doctor and their patient, which is why CMA has removed policy that outright objects to physicians aiding terminally ill patients in end of life options. We believe it is up to the individual physician and their patient to decide voluntarily whether the End of Life Option Act is something in which they want to engage.”1

The American Medical Student Association (AMSA) 30,000+ members
Committed to improving healthcare and healthcare delivery; improving medical education; involving its members in the social, moral and ethical obligations of the profession of medicine.

“The American Medical Student Association: 1. SUPPORTS passage of aid-in-dying laws that empower terminally ill patients who have decisional capacity to hasten what might otherwise be a protracted, undignified or extremely painful death. Aid in dying should not, for any purpose, constitute suicide, assisted suicide, mercy killing or homicide.”2

A growing number of national and state organizations representing healthcare professionals have endorsed or taken a neutral position on medical aid in dying as an end-of-life option for mentally capable, terminally ill adults. The complete statements also express Compassion & Choices’ view that terminally ill people deserve information about and access to the full range of end-of-life options, including hospice and palliative care, terminal sedation, voluntarily stopping eating and drinking (VSED), and medical aid in dying.

American Public Health Association (APHA) 50,000 Members
Committed to improving health of the public and achieving equity in health status.

“The American Public Health Association (APHA) has long recognized patients’ rights to self-determination at the end of life and that for some terminally ill people, death can sometimes be preferable to any alternative. Accordingly, the American Public Health Association:

Supports allowing a mentally competent, terminally ill adult to obtain a prescription for medication that the person could self-administer to control the time, place and manner of his or her impending death, where safeguards equivalent to those in the Oregon DDA are in place. Rejects the use of inaccurate terms such as “suicide” and “assisted suicide” to refer to the choice of a mentally competent, terminally ill patient to seek medications to bring about a peaceful and dignified death.”3

CompassionAndChoices.org
info@compassionandchoices.org
American Medical Women’s Association (AMWA)  
4,000 members

Physicians, residents, medical students and healthcare professionals dedicated to advancing women in medicine and improving women’s health.

1. AMWA supports the right of terminally ill patients to hasten what might otherwise be a protracted, undignified or extremely painful death. 2. AMWA believes the physician should have the right to engage in practice wherein they may provide a terminally ill patient with, but not administer, a lethal dose of medication and/or medical knowledge, so that the patient can, without further assistance, hasten his/her death. This practice is known as aid in dying. 11. AMWA supports the passage of aid-in-dying laws that empower mentally competent, terminally ill patients and protect participating physicians, such as that passed in Oregon, the Oregon Death With Dignity Act. 4

The American College of Legal Medicine (ACLM) 700 members

Professional society concerned with addressing issues that arise at the interface of law and medicine.

“BE IT RESOLVED: That the ACM recognizes patient autonomy and the right of a mentally competent, though terminally ill, person to hasten what might otherwise be objectively considered a protracted, undignified or painful death, provided, however, that such person strictly complies with law specifically enacted to regulate and control such a right; and BE IT FURTHER RESOLVED: That the process initiated by a mentally competent, though terminally ill, person who wishes to end his or her suffering and hasten death according to law specifically enacted to regulate and control such a process shall not be described using the word "suicide", but, rather, as a process intended to hasten the end of life.”5

American Academy of Hospice & Palliative Medicine (AAHPM)  
5,000 members

Organization for physicians, nurses and others specializing in hospice and palliative medicine.

“Excellent medical care, including state-of-the-art palliative care, can control most symptoms and augment patients' psychosocial and spiritual resources to relieve most suffering near the end of life. On occasion, however, severe suffering persists; in such a circumstance a patient may ask his physician for assistance in ending his life by providing physician-assisted death (PAD). PAD is defined as a physician providing, at the patient's request, a lethal medication that the patient can take by his own hand to end otherwise intolerable suffering. The term PAD is utilized in this document with the belief that it captures the essence of the process in a more accurately descriptive fashion than the more emotionally charged designation physician-assisted suicide. AAHPM takes a position of 'studied neutrality' on the subject of whether PAD should be legally regulated or prohibited, believing its members should instead continue to strive to find the proper response to those patients whose suffering becomes intolerable despite the best possible palliative care. Whether or not legalization occurs, AAHPM supports intense efforts to alleviate suffering and to reduce any perceived need for PAD.”6

CompassionAndChoices.org
info@compassionandchoices.org
Resources


Medical Aid in Dying Improves Care at the End of Life

What Is Palliative Care?

Palliative care, sometimes called "comfort care," is person- and family-centered care that optimizes quality of life by anticipating, preventing and treating suffering. Palliative care throughout the continuum of illness addresses physical, intellectual, emotional, social and spiritual needs and facilitates patient autonomy, access to information and choice in care.¹

How Does Medical Aid in Dying Improve Palliative Care Outcomes?

Medical aid in dying — one option on the palliative care spectrum — enhances palliative care in several ways. Prior to providing a medical aid-in-dying prescription, physicians are required to confirm that their patient is fully informed of all their care options.

Palliative care physicians report that a patient’s questions about medical aid in dying prompt in-depth conversations between doctors and patients about the full-range of end-of-life care options, including hospice, pain management and emotional support in addition to aid in dying.

Numerous studies in Oregon and Washington, along with a host of national surveys, link the availability of medical aid in dying as a palliative care option to a number of positive outcomes for end-of-life care. A few of these findings are summarized below:

> Research conducted in Oregon suggests that having medical aid in dying as an option relieves worries about future discomfort, pain and loss of control. A study of hospice nurses and social workers in Oregon reported that symptoms of pain, depression, anxiety, extreme air hunger and fear of the process of dying were more pronounced among hospice patients who did not request aid-in-dying medication,² indicating a strong palliative care benefit for having an aid-in-dying prescription on hand. University of Pennsylvania’s Center for Bioethics director Arthur Caplan has said, "...the Oregon law probably has benefited many more people than have actually used it."³

> Medical aid in dying promotes appropriate hospice use. A Journal of Palliative Medicine report on patterns of hospice use noted that Oregon was in both the highest quartile of hospice use and the lowest quartile of potentially concerning patterns of hospice use.⁴ Vermont, where medical aid in dying was authorized in 2013, was in the lowest quartile of all three potentially concerning patterns of hospice use examined.⁵ Posited the researchers, "...it is possible that the Oregon Death With Dignity Act has resulted in or at least reflects more open conversation and careful evaluation of end-of-life options."⁶ Indeed, 30 percent of Oregon doctors responding to a 1999 survey said that after voters approved medical aid in dying, the number of patients they referred to hospice increased.⁷ Some hospice programs in Oregon, according to the Annals of Internal Medicine, reported a 20 percent jump in referrals since the vote.⁸
Medical aid in dying helps family caregivers prepare for and accept a terminally ill person’s death. Respondents to the previously cited Oregon hospice nurse/social worker study reported family caregivers of patients who chose medical aid in dying “were more likely to find positive meaning in caring for the patient and were more prepared for and accepting of the patient’s death” than family caregivers of patients not requesting medical aid in dying.2 A mental health survey of 95 Oregonian families whose loved ones chose medical aid in dying after exhausting other palliative care options yielded similar results.8

Medical aid in dying has resulted in better physician palliative care training. The Journal of Palliative Medicine article referenced above also suggested that medical aid in dying in Oregon has resulted in “more appropriate palliative care training of physicians,”7 and a New England Journal of Medicine article likewise noted that 88 percent of responding Oregon doctors who had cared for terminally ill patients reported actively improving their knowledge of pain management for those patients.9

Terminally ill people who choose medical aid in dying are overwhelmingly in hospice care and able to die at home. In Oregon, 93 percent of adults who used medical aid-in-dying prescriptions in 2014 were enrolled in hospice care, and 90 percent died at home.10 In Washington state, 69 percent were enrolled in hospice care, and 92 percent were able to die at home.11

Since the authorization of aid in dying, Oregon hospitals have expanded palliative care for individuals with terminal and life-threatening illnesses. The Annals of Internal Medicine reported a number of Oregon hospitals had developed or expanded the scope of hospice-modeled “comfort care consultation teams” in the wake of Oregon’s Death With Dignity Act’s passage. According to the Annals article, “These interdisciplinary teams act as consultants to enhance comfort care not only for terminally ill patients but for other patients who have life-threatening illnesses in various inpatient and outpatient settings.”12

Adults in Oregon and Washington, where medical aid in dying is authorized, are more knowledgeable about palliative, end-of-life and hospice care. A poll conducted by National Journal and Regence Foundation found that both Oregonians and Washingtonians were more familiar with the terminology “end-of-life care” than the rest of the country and residents of both states are slightly more aware of the terms palliative and hospice care.13
Resources

1 An Explanation of Palliative Care. Available from
http://www.nhpco.org/palliative-care-4

of Oregon nurses and social workers with hospice patients who
requested assistance with suicide. The New England Journal of
Medicine. 347 (8): 585

3 Don Colburn. (2005, March 11) Fewer Turn to Assisted Suicide.
The Oregonian. Available from
http://lists.opn.org/pipermail/right-to-die_lists.opn.org/2005-
March/000730.html

4 Wang, S, Aldridge, MD, Gross, CP, Canavan, M, Cherlin, E,
Johnson-Hurzeler, R., et al. (2015) Geographic Variation of
Hospice Use Patterns at the End of Life. Journal of Palliative
Medicine. 18(9), 775.

5 Ibid., p.778.

6 Ganzini, L, Nelson, HD, Lee, MA, Kraemer, DF, Schmidt, TA,
Delorit, MA. (2001) Oregon Physicians’ Attitudes About and
Experiences with end-of-life care since passage of the Oregon
death with dignity act. JAMA. 285(18): 2365

7 Lee, M&A, & Tolle, S.W. (1996) Oregon’s assisted suicide vote:

Mental health outcomes of family members of Oregonians who
request physician aid in dying. Journal of Pain Symptom
Management. 38, 807-815

9 Ganzini, L, Nelson, HD, Schmidt, TA, Kraemer, DF, Delorit,
MA, Lee, MA. (2000) Physicians’ experiences with the Oregon
death with dignity act. New England Journal of Medicine. 342:
558.

10 Oregon Public Health Division, Oregon’s Death With Dignity
Act-2014, page 2, ninth bullet. Available from
https://public.health.oregon.gov/ProviderPartnerResources/Eval
uationResearch/DeathwithDignityAct/Documents/year17.pdf

11 Washington State Department of Health 2014 Death with
http://www.doh.wa.gov/portals/1/Documents/Pubs/422-109-
DeathWithDignityAct2014.pdf

12 Lee, M,A, & Tolle, S.W. (1996) Oregon’s assisted suicide vote:

13 National Journal/Regence Foundation Poll, “Living Well at the
End of Life,” 2010-2011. Available from
http://syndication.nationaljournal.com/communications/Nationa
lJournalRegenceToptlines.pdf