

Written Testimony on HB 5417, An Act Concerning End-of-life Care
Ashley Cardenas, Policy & Programs Director, Compassion & Choices
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Introduction

Good morning Chair and Members of the Committee. My name is Ashley Cardenas, Policy & Programs Director for Compassion & Choices, the nation's oldest and largest nonprofit organization working to improve care and expand choice at the end of life.^{1,2,3,4,5} Compassion & Choices advocates for legislation to improve the quality of end-of-life care for terminally ill patients and affirms their right to determine their own medical treatment options as they near the end of life. We applaud the efforts of introducing this important legislation and appreciate the opportunity to offer our expertise as the leading national non-profit dedicated to expanding choice at the end of life.

While there are provisions contained in HB 5417, which we do not support, we are here today to express our support for the overall goals of the legislature to improve the quality of end-of-life care and authorize medical aid in dying for Connecticut's terminally ill patients and their families.

What is Medical Aid in Dying?

Medical aid in dying refers to a medical practice in which a mentally capable, terminally ill adult with six months or fewer to live may request from his or her physician a prescription for a medication that the he or she can take to peacefully pass in their sleep when, and if, their suffering becomes unbearable.

For Some, Comfort Care and Pain Management Is Not Enough

While palliative care and hospice programs may provide extraordinary comfort and work wonders for many dying people and their loved ones, there are times when even the best palliative options cannot alleviate pain and suffering. Other symptoms, like fatigue,

¹ Compassion & Choices brought landmark federal cases establishing that dying patients have the right to aggressive pain management, including palliative sedation. *Vacco v. Quill*, 521 U.S. 793 (1997); *Washington v. Glucksberg*, 521 U.S. 702 (1997).

² Compassion & Choices drafted and sponsored introduction of legislation requiring comprehensive counseling regarding end-of-life care options. See, California Right to Know End-of-Life Options Act, CAL. HEALTH & SAFETY CODE §442.5; New York Palliative Care Information Act, N.Y. PUB. HEALTH LAW § 2997-c.

³ For example, Compassion & Choices is pursuing accountability for failure to honor a patient's wishes as documented in a POLST, *DeArmond v Kaiser*, No. 30-2011-00520263 (Superior Court, Orange County, CA). In another case, Compassion & Choices represented a family in bringing into the public eye a situation where patient wishes to forego food and fluid were obstructed. See Span, "Deciding to Die, Then Shown the Door," *The New York Times*, Aug. 24, 2011, available at <http://newoldage.blogs.nytimes.com/2011/08/24/deciding-to-die-then-shown-the-door/?ref=health>; Uyttebrouck, "Couple Transported Out of Facility After Refusing Food," *Albuquerque Journal*, Jan. 08, 2011, available at <http://www.abqjournal.com/news/metro/08232859metro01-08-11.htm>.

⁴ Compassion & Choices brought two federal cases to the United States Supreme Court urging recognition of a federal constitutional right to choose aid in dying. *Washington v. Glucksberg*, 521 U.S. 702 (1997); *Vacco v. Quill*, 521 U.S. 793(1997). Compassion & Choices was in leadership in the campaigns to enact the Death with Dignity Acts in Oregon and Washington. OR. REV. STAT. § 127.800 (2007); WASH. REV. CODE ANN. § 70.245 (West 2011).

⁵ See supra n. 1, Bergman, Tomlinson, Tolliver, Hargett; See supra n. 3, DeArmond.

breathlessness, nausea, vomiting, rashes and open, draining sores and wounds may be untreatable.

Despite the availability of palliative care and pain management, up to 51% of patients⁶ experience pain at the end of life. The prevalence of pain has been noted to increase significantly in the last 4 months of life and reaching as high as 60% in the last month of life.⁷ Additionally, breakthrough pain (severe pain that erupts while a patient is already medicated with a long-acting painkiller) remains a challenge for many patients. It has been estimated that between 65% and 85% of patients with cancer experience significant pain.⁸

Requests for Medical Aid in Dying are not a Failure of Hospice or Palliative Care

Requests for medical aid in dying are not a failure of hospice or palliative care. Good hospice services and palliative care do not reduce the need of medical aid in dying as an end-of-life care option. Terminally ill people should have a full range of end-of-life care options, whether for disease-specific treatment, palliative care, refusal of life-prolonging treatment and the right to request medication the patient can choose to take to shorten a prolonged and difficult dying process. Only the dying person can decide whether their pain and suffering is too great to withstand. The option of medical aid in dying puts the decision-making power where it belongs: with the dying person.

Voter Support for Medical Aid in Dying is Strong

Numerous polls from a variety of sources, both nationally and at the state level, demonstrate that the American public consistently supports medical aid in dying. In 2016, a Lifeway Research survey⁹ put national support for medical aid in dying at 67%. Majority support spanned a variety of demographic groups, including White Americans (71%), Hispanic Americans (69%), more than half of Black, Non-Hispanic Americans (53%); adults aged 18 to 24 (77%), 35 to 44 (63%) and 55 to 64 (64%); with some college education (71%), with graduate degrees (73%) and with high school diplomas or less (61%). Majority support also included most faith groups, including Christians (59%), Catholics (70%), Protestants (53%), those of other religions (70%) and those who identified as non-religious (84%).

Physician Support for Medical Aid in Dying is Strong

⁶ Sykes, N., & Thorns, A. (2003). The use of opioids and sedatives at the end of life. *The Lancet Oncology*, 4(5), 312–318. Available from: http://www.lidsinger.stjohnsem.edu/ThM_590_Intro-Bioeth/15_palliative_care/2003%20Lancet%20-%20The%20use%20of%20opioids%20and%20sedatives%20at%20the%20end%20of%20life.pdf

⁷ Smith, A. K., Cenzer, I. S., Knight, S. J., Puntillo, K. A., Widera, E., Williams, B. A., Boscardin, W. J., & Covinsky, K. E. (2010). The epidemiology of pain during the last 2 years of life. *Annals of Internal Medicine*, 153(9), 563–569. Available from: <http://annals.org/aim/article/746344/epidemiology-pain-during-last-2-years-life>

⁸ Jeri Ashley, RN, MSN, AOCNS, CCRS; James T. D'Olimpio, MD, FACP; Breakthrough Pain in Patients with Cancer: Essential Concepts for Nursing, Pharmacy, Oncology, and Pain Management Medscape, 11/19/2009. Available from: <http://www.medscape.org/viewarticle/712261>

⁹ American Views on Assisted Suicide, Lifeway Research, September, 2016. Available from: <http://lifewayresearch.com/wp-content/uploads/2016/12/Sept-2016-American-Views-Assisted-Suicide.pdf>

Among U.S. physicians, support for medical aid in dying is also strong. A December 2016 Medscape poll¹⁰ of more than 7,500 U.S. physicians from more than 25 specialties demonstrated a significant increase in support for medical aid in dying from 2010. Today well over half (57%) of the physicians surveyed endorse the idea of medical aid in dying, agreeing that “Physician assisted death should be allowed for terminally ill patients.” An even more recent Medscape poll¹¹ conducted in June 2017, found that some 62% of doctors who practice in states that do not allow assisted death said they had been in a situation in which they wished the patient could have been able to exercise that right. Additionally, 56% of doctors who responded said they thought the passage of physician-assisted dying laws was a positive development. This is not just support for but it being "A positive Development!"

Most of the medical associations in authorized states currently have neutral positions on medical aid in dying including Oregon,¹² California,¹³ and Colorado.¹⁴ Additionally numerous professional medical organizations have endorsed or dropped their opposition to medical aid in dying in response to growing support for this palliative care option among physicians and the public.¹⁵

HB 5417, An Act Concerning End-of-life Care

The bill you are considering is modeled after the Oregon Death with Dignity Act, which was drafted more than 20 years ago, during a time when no other state authorized the medical practice of medical aid in dying. In a growing number of jurisdictions, lawmakers like yourselves are examining the Oregon experience over the last 19 years (1998-2016) and developing legislative approaches that are appropriate for them. HB 5417 is sound legislation for a compassionate medical practice based on a proven track record.

Established Process: Eligibility Criteria and Core Safeguards

HB 5417 establishes strict eligibility criteria, as well as guidelines that meet the highest standard of care for the medical practice of aid in dying, as described in clinical criteria published in the prestigious and peer reviewed Journal of Palliative Medicine.¹⁶ To be eligible for aid-in-dying medication, an adult must be terminally ill, with a prognosis of six months or less to live and

¹⁰ Medscape Ethics Report 2016: Life, Death, and Pain, December 23, 2016. Available from:

<http://www.medscape.com/features/slideshow/ethics2016-part2#page=2>

¹¹ Medscape Poll, June 2017, Physician Assisted Death: Where do you stand? Available from:

<http://www.medscape.com/viewarticle/874341>

¹² Oregon Medical Association. Excerpted from: WWS Section on Hospice-End of life Care-Death & Dying. Date unknown. Available from

<https://drive.google.com/file/d/0B3luDjCAxxv7clQwYzdlWjZEB0xqbFE4eWRHbTMzNVhsck00/view?usp=sharing>

¹³ California Medical Association. Excerpted from: CMA changes stance on physician aid in dying, takes neutral position on End of Life Option Act. June 2, 2015. Available at

<http://www.cmanet.org/news/detail/?article=cma-changes-stance-on-physician-aid-in-dying>.

¹⁴ Colorado Medical Society, Statement by CMS President-elect Katie Lozano, MD, FACR, regarding Ballot Proposition 106. Available from:

<http://www.cms.org/articles/statement-by-cms-president-elect-katie-lozano-md-facr-regarding-ballot-prop>

¹⁵ Healthcare Professional Organizations that Recognize Medical Aid in Dying, Compassion & Choices Fact Sheet, Available from: <https://drive.google.com/file/d/0B3luDjCAxxv7UTdKemdGbW81Zms/view>

¹⁶ Orentlicher, D., Pope, T.M., Rich, B.A. (2015) Clinical Criteria for Physician Aid in Dying. Journal of Palliative Medicine. 18(x): 1-4. Available from:

<https://www.compassionandchoices.org/wp-content/uploads/2016/04/Clinical-Criteria-for-Aid-in-Dying.pdf>

mentally capable of making his or her own healthcare decisions. In addition to the strict eligibility criteria, HB 5417 establishes core safeguards, including that the attending physician must inform terminally ill adults requesting medical aid in dying about other end-of-life care options including comfort care, hospice care and pain control and the terminally ill adult must self-administer the aid-in-dying medication.

Additional Regulatory Requirements

HB 5417 requires that a consulting physician must confirm the terminal diagnosis, prognosis of six months or less to live and mental capability of the terminally ill individual requesting this option. If either the attending or consulting physician is unable to determine whether the individual has mental capacity in making the request, a mental health professional (psychiatrist or psychologist) must evaluate the individual and ensure that they are capable of making their own healthcare decisions prior to a prescription being written.

The terminally ill adult must make multiple requests to their doctor; the doctor must offer the individual multiple opportunities to withdraw their request; and inform the individual that they may withdraw their request at any time or choose not to take the medication.

Voluntary Participation

A healthcare provider may choose whether to voluntarily participate in medical aid in dying. The bill ensures that no doctor or pharmacist is obligated to prescribe or dispense aid-in-dying medication. However, if a doctor is unable or unwilling to honor a patient's request and the patient transfers his or her care to a new provider, the prior provider must transfer upon request a copy of the patient's relevant medical records to the new physician. Those physicians who do choose to participate are protected under the legislation from criminal and civil liability, and professional discipline, if they comply with the law and act within the standards of medical care.

Criminal Conduct

Additionally, HB 5417 establishes that any person who, without authorization from the patient, willfully alters, forges, conceals or destroys an instrument, a reinstatement, or revocation of an instrument or any other evidence or document reflecting the terminally ill individual's desires and interests with the intent and effect of hastening the death of the individual is guilty of a crime.

A Combined Forty Years of Experience Demonstrates Medical Aid in Dying is a Safe and Trusted Practice

Medical aid in dying is a safe and trusted practice. Opponents of medical aid-in-dying legislation try to use scare tactics by painting a dark, false picture of abusive family members coercing their terminally ill loved ones into fraudulently requesting the medication and taking it against their will. These scare tactics includes concerns the law would target the disabled, elderly, frail, uninsured and other vulnerable groups. *These dire predictions simply do not happen.* In the more than 40 combined years of experience with medical aid in dying in the six authorized states, California, Colorado, Montana, Oregon, Vermont and Washington, as well as the District of Columbia, there has not been a single instance of documented coercion or abuse. The experience in these seven authorized jurisdictions shows us these laws have worked as intended, with none of the problems opponents had predicted.

Indeed, rather than posing a risk to patients or the medical profession, the Oregon Death with Dignity Act has galvanized significant improvements in the care of the terminally ill and dying in that state. A survey of doctors about their efforts to improve end-of-life care since medical aid in dying became available showed 30% of responding physicians had increased referrals to hospice care, and 76% made efforts to improve their knowledge of pain management.¹⁷ In addition to the improvement of end-of-life care, the option of medical aid in dying has psychological benefits for both the terminally ill and the healthy.¹⁸ The availability of the option of medical aid in dying gives the terminally ill person more autonomy, control and *choice*, the overwhelming motivational factor behind the decision to request assistance in dying.¹⁹ Healthy Oregonians know that if they ever face a terminal illness, they will have this additional end-of-life care option and the peace of mind it provides. And importantly, surviving loved ones of patients who choose medical aid in dying suffer none of the adverse mental health impacts that come when a loved one commits suicide.²⁰

Medical Aid in Dying is Not Euthanasia

Medical aid in dying is fundamentally different from euthanasia. As noted earlier, medical aid in dying is authorized in six states as well as the District of Columbia. With medical aid in dying, the terminally ill person must take the medication themselves, and therefore, always remains in control. Euthanasia is commonly given as a lethal injection by a third party. It is often performed on somebody who does not have a terminal diagnosis and is illegal throughout the United States. Compassion & Choices does not support euthanasia because someone else – not the dying person – chooses and acts to cause death.

Medical Aid in Dying is Not Suicide

Factually, legally and medically speaking, it is inaccurate to equate medical aid in dying with suicide or assisted suicide. People who consider medical aid in dying find the suggestion that they are committing suicide deeply offensive, stigmatizing and inaccurate. The Oregon, Washington, Vermont, California, Colorado and District of Columbia 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.”

¹⁷Ganzini L, Nelson HD, Lee MA, Kraemer DF, Schmidt TA, Delorit MA. Oregon Physicians' Attitudes About and Experiences With End-of-Life Care Since Passage of the Oregon Death with Dignity Act. *JAMA*. 2001;285(18):2363-2369. doi:10.1001/jama.285.18.2363

¹⁸ Kathy L. Cerminara & Alina Perez, *Empirical Research Relevant to the Law: Existing Findings and Future Directions, Therapeutic Death: A Look at Oregon's Law*, 6 *PSYCHOL. PUB. POL'Y & L.* 503, 512–13 (2000).

¹⁹ *Id.* (acknowledging concerns about negative effects of aid in dying, but the data from Oregon in one year justifies optimistic view); Smith et al., *supra*, at 445, 449. See also Linda Ganzini et al., *Oregon Physicians' Perceptions of Patients who Request Assisted Suicide and Their Families*, 6 *J. PALLIATIVE MED.* 381, 381 (2003) (finding physicians receiving requests for lethal medication perceive patients as wanting to control their deaths); Linda Ganzini et al., *Experiences of Oregon Nurses and Social Workers with Hospice Patients who Requested Assistance with Suicide*, 347 *NEW ENG. J. MED.* 582, 582 (2002) (showing nurses and social workers rated desire to control circumstances of death as most important reason for requesting aid in dying).

²⁰ Linda Ganzini et al. [Mental Health Outcomes of Family Members of Oregonians Who Request Physician Aid in Dying](#), 38 *Journal of Pain and Symptom Management* 807 (2009).

This is a fact 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 medical aid in dying is simply choosing not to prolong a difficult and painful dying process.

Medical Aid in Dying Is a Personal Decision

Every religion has its own values, tenets and rituals around death. A person's individual beliefs are an important factor in their understanding of and approach to dying. While some faiths counsel their adherents that advancing the time of death to avoid suffering is immoral, others just as strongly counsel the dying and their families to leave this life in the manner most meaningful to them. Choosing medical aid in dying is only one end-of-life care option. Those who are strongly opposed need not choose it. For those who face unbearable suffering, this option can give them both courage and hope, allowing them to live fully as long as possible and to pass peacefully when death is imminent. This is a personal decision that only the individual can make.

Provisions That Compassion & Choices Does Not Support and Friendly Amendments

When evaluating regulations within the legislation it is very important to consider the balance between ensuring a patient is safe and making sure that we are not placing undue burdens on them. Adding the additional requirements and regulations described in HB 05417 will not make medical aid-in-dying safer in the state of Connecticut; it will only create additional barriers that will make it nearly impossible for dying people to use this end-of-life care option. There are hundreds of examples of desperate people trying to access the law and running out of time and not a single example of abuse or coercion. The evidence and facts demonstrate that current medical aid-in-dying laws' strict eligibility requirements and core safeguards work as intended by affirming patient autonomy while ensuring a high standard of care and preventing abuse.

Compassion & Choices supports bills modeled after the Oregon Death with Dignity Act, which has demonstrated for over 20 years that medical aid-in-dying laws work as intended. However, after two decades of experience, it is no longer the ideal model for crafting new legislation. Any legislative body considering introducing legislation to authorize medical aid in dying can and should use the opportunity to refine the bill language based upon the Oregon experience and lessons learned. As such, there are several minor friendly amendments that Compassion & Choices would like to propose to HB 05417, which we believe will greatly strengthen the bill.

The proposed bill requires one oral request and two written requests.

The standard of care for medical aid in dying has developed over the course of more than 40 years of combined practice in the seven authorized jurisdictions which have authorized the practice. The Journal of Palliative Medicine published [clinical criteria for medical aid in dying](#) that physicians use to ensure that the practice meets the highest standards of medical care, this includes an advised protocol for responding to a terminally ill individual's request for medical aid in dying. While the clinical criteria does support a waiting period between the terminally ill patient's request and the writing of a prescription for aid-in-dying medication, multiple requests are not recommended or supported.

Under existing medical aid-in-dying laws and all legislation proposed in other states require a terminally ill individual to make two oral requests and submit one written request. This has been a political concession made in each state as there is no evidence to suggest that requiring

multiple requests enhances patient safety. Requiring multiple requests can however, operate to prolong unbearable and unnecessary suffering; deprive terminally ill patients from effectively exercising the choice they have made to use medical aid in dying; and deprive them of autonomy, self-determination and what they consider to be the most peaceful and dignified death. Additionally, requiring multiple requests, especially in a particular format as required by HB 05217, unfairly stigmatizes and discriminates against terminally ill patients who choose medical aid in dying over other end-of-life care options. No other end-of-life care choice (including removal from a ventilator, palliative sedation or VSED) require multiple requests.

Compassion & Choices supports informed healthcare decision-making that ensure thoughtful choices. However, Compassion & Choices, does not support a mandate for multiple written requests for medical aid in dying. This requirement, in addition to the mandate for each written request to be witnessed by two different people, totaling four (4) witnesses does nothing but erect yet another barrier for terminally ill individuals seeking the option of medical aid in dying. As such, Compassion & Choices strongly suggests that HB 05417 be amended to reflect the regulatory requirements for making a request for medical aid in dying consistent with other authorized states as demonstrated below. Newly proposed language is underlined, language suggested for removal is ~~struck through~~.

Sec. 2. (NEW) (Effective October 1, 2018) (a) A patient who (1) is an adult, (2) is competent, (3) is a resident of this state, (4) has been determined by such patient's attending physician to have a terminal illness, and (5) has voluntarily expressed his or her wish to receive aid in dying, may request aid in dying by making two oral requests and one written requests to such patient's attending physician pursuant to sections 3 and 4 of this act.

Sec. 3. (NEW) (Effective October 1, 2018) (a) A patient wishing to receive aid in dying medication shall submit two written oral requests, a minimum of fifteen days apart, and one written request to such patient's attending physician in substantially the form set forth in section 4 of this act, directly to the individual's attending physician. A patient's second written request for aid in dying shall be submitted not earlier than fifteen days after the date on which a patient submits the first request.

Sec. 5. (NEW) (Effective October 1, 2018) (a) A qualified patient may rescind his or her request for aid in dying at any time and in any manner without regard to his or her mental state.

(b) An attending physician shall offer a qualified patient an opportunity to rescind his or her request for aid in dying at the time such patient ~~submits~~ makes a second oral written request for aid in dying to the attending physician.

Sec. 6. (NEW) (*Effective October 1, 2018*) When an attending physician is presented with a patient's first ~~written~~ request for aid in dying made pursuant to sections 2 to 4, inclusive, of this act, the attending physician shall:...

Sec. 9. (NEW) (*Effective October 1, 2018*) (a) After an attending physician and a consulting physician determine that a patient is a qualified patient, in accordance with sections 6 to 8, inclusive, of this act and after such qualified patient ~~submits~~

makes a second oral request for aid in dying in accordance with sections 3 and 4 of this act, the attending physician shall:...

The proposed bill mandates each of the two required written requests must be witnessed by two different people, totaling four (4) witnesses-none of which may be a family member or person in a position to inherit any portion of the terminally ill individual's estate upon death.

Under existing medical aid-in-dying laws and all legislation proposed in other states, two physicians must certify that the terminally ill person's request is informed, free of undue influence or coercion, and two witnesses who personally know the dying person have to attest that the person is making a voluntary, informed decision, without undue influence or coercion. One of the two required witnesses must not be a family member or person in a position to inherit any portion of the terminally ill individual's estates upon death.

HB 05417 imposes an incredible burden on terminally ill individuals seeking this end-of-life care option by mandating a total of four (4) witnesses to the two written requests, and prohibiting a family member or person in a position to inherit any portion of the terminally ill individual's estates upon death from serving as a witness. Additionally, the bill excludes both the attending physician and any owner, operator or employee of a healthcare facility where the terminally ill individual is a resident or receiving medical treatment from serving as a witness.

Such a requirement is not only unnecessary to protect patients but it unfairly stigmatizes and discriminates against patients who choose medical aid in dying instead of other end-of-life care choices. Terminally ill patients must make a total of three requests (one oral and two written as currently required,) and must be deemed by two separate physicians to have made a voluntary, informed decision, without undue influence or coercion. To require a terminally ill individual to go to such extraordinary lengths to prove their willingness and capability is to suggest that terminally ill people who choose medical aid in dying are less capable of making their own decisions than people who chose options such as withdrawing or withholding life-sustaining treatment or palliative sedation, which do not require such an onerous regulatory process.

Additionally, such an unnecessary mandate will prevent some terminally ill individuals from being able to carry out their choice about how to die in the event they are unable to identify willing individuals who meet this stringent criteria or they may forgo the final steps required to obtain the medication to spare known individuals from being forced to travel long distances to serve as a witness.

As such, Compassion & Choices strongly suggests that HB 05417 be amended to reflect the regulatory requirements for witnesses consistent in other medical aid-in-dying laws, as demonstrated below. Newly proposed language is underlined, language suggested for removal is ~~struck through~~.

Sec. 3. (NEW) (Effective October 1, 2018) (a) A patient wishing to receive aid in dying medication shall submit two ~~written-oral~~ requests, a minimum of fifteen days apart and a written request to such patient's attending physician in substantially the form set forth in section 4 of this act, directly to the individual's attending physician. ~~A patient's second written request for aid in dying shall be submitted not earlier than fifteen days after the date on which a patient submits the first request.~~

A valid written request for aid in dying under sections 1 and 2 of this act and sections 4 to 19, inclusive, of this act shall be signed and dated by the patient. Each request shall be witnessed by ~~at least~~ two persons in the presence of the patient. Each person serving as a witness shall attest, in writing, that to the best of his or her knowledge and belief that the individual requesting the aid-in-dying medication is all of the following: (1) ~~the patient appears to be of sound mind;~~ An individual who is personally known to them or has provided proof of identity; (2) ~~the patient is acting voluntarily and not being coerced to sign the request;~~ An individual who voluntarily signed this request in their presence; and (3) ~~the witness is not:~~ An individual whom they believe to be of sound mind and not under duress, fraud, or undue influence.

~~(b) No person serving as a witness to a patient's request to receive aid in dying shall be:~~ Only one of the two witnesses described in this section may meet either of the following criteria:

- (1) A relative of ~~such the~~ patient by blood, marriage or adoption;
- (2) At the time the request is signed, entitled to any portion of the estate of the patient upon the patient's death, under any will or by operation of law;
- ~~(3) An owner, operator or employee of a health care facility where the patient is a resident or receiving medical treatment, or;~~
- (3) ~~such~~ The patient's attending physician at the time the request is signed.

Subsequently, the Declaration of Witness must also be revised to reflect this amendment as follows.

By initialing and signing below on the date the person named above signs, I declare that:

1. The person making and signing the request is personally known to me or has provided proof of identity;
2. The person making and signing the request signed this request in my presence on the date of the person's signature;
3. The person making the request appears to be of sound mind and not under duress, fraud or undue influence;
4. ~~I am not the attending physician for the person making the request;~~ Is not a patient for whom either of us is attending physician;
5. ~~The person making the request is not my relative by blood, marriage or adoption;~~
6. ~~I am not entitled to any portion of the estate of the person making the request upon such person's death under any will or by operation of law; and~~
7. ~~I am not an owner, operator or employee of a health care facility where the person making the request is a resident or receiving medical treatment.~~

NOTE: One witness shall not be a relative (by blood, marriage or adoption) of the person signing this request, shall not be entitled to any portion of the person's estate upon death.

The proposed bill unnecessarily restricts attending physicians and consulting physicians from “routinely sharing office space.”

Given the challenges presented by a scarce number of medical providers and rampant healthcare organization mergers, unnecessarily restricting the working relationships of physicians stands not only to limit access to medical aid in dying, but may impact the overall quality of end-of-life care, by disrupting the terminally ill patient's continuity of care.

Regardless of one's office location, the consulting provider must perform an independent assessment; evaluating a terminally ill individual's request for medical aid in dying, eligibility and capacity to make an informed decision. This is already part of the standard of care, reaffirmed by the process outlined in HB 05417. Furthermore, any provider who does not meet this standard would not be afforded the protections that HB 05417 provides. C&C strongly recommends removal of this provisions in the bill as demonstrated below. Newly proposed language is underlined, language suggested for removal is ~~struck through~~.

Section 1. (5) "Consulting physician" means a physician other than a patient's attending physician who ~~(A) is qualified by specialty or experience to make a professional diagnosis and prognosis regarding a patient's terminal illness;~~ and ~~(B) does not routinely share office space with a patient's attending physician;~~

The bill too narrowly defines the ways which a terminally ill individual must demonstrate residency as a requirement of eligibility.

By limiting the allowable evidence of residency to a Connecticut driver's license, a valid voter registration record or any other government-issued document that the attending physician reasonably believes demonstrates that the patient is a current resident of this state; may unintentionally limit access to medical aid in dying for otherwise qualified terminally ill individuals who reside in the state. The majority of people want to die at home, wherever home may be. In places like Montana where there is no residency requirement, nothing indicates that individuals are traveling there for the explicit purpose of accessing medical aid in dying. As such, Compassion & Choices strongly suggests expanding the acceptable documents demonstrating residency. Newly proposed language is underlined, language suggested for removal is ~~struck through~~.

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(2) Require the patient to demonstrate residency in this state by presenting:
(A) A Connecticut driver's license or state issued identification card;
(B) A valid voter registration record authorizing the patient to vote in this state; ~~or~~
(C) Evidence that the person owns or leases property in Connecticut;
(D) Filing of a Connecticut tax return for the most recent tax year, or
(~~E~~) Any other ~~government-issued~~ document that the attending physician reasonably believes demonstrates that the patient is a current resident of this state;

The bill limits the additional capability assessment of the terminally ill applicant for medical aid in dying to a psychiatrist or psychologist.

Given the shortage of mental health providers across the country, and the often long waiting times to confirm an appointment, mandating that only a psychiatrist or psychologist is allowed to perform an additional capability assessment stands to severely limit, and in many cases make it impossible, for some terminally ill individuals to access medical aid-in-dying.

Conducting capability assessments is part of the training and routine practice for licensed clinical social workers. Additionally, licensed clinical social workers are mentioned throughout the bill as being available for counseling services. Compassion & Choices recommends including licensed clinical social workers under the scope of mental health professionals in the proposed bill as this provision would ensure that terminally ill patients requiring an additional capability assessment are less likely to be denied this option, based solely on a lack of available

mental health specialists. Newly proposed language is underlined, language suggested for removal is ~~struck through~~.

Section 1.

(10) "Licensed mental healthcare professional" means a psychiatrist, psychologist or clinical social worker licensed under [state code/regulation].

~~(15) "Psychiatrist" means a physician specializing in psychiatry and licensed pursuant to chapter 370 of the general statutes;~~

~~(16) "Psychologist" means a person licensed to practice psychology pursuant to chapter 383 of the general statutes;~~

Sec. 8. (NEW) (Effective October 1, 2018) (a) If, in the medical opinion of the attending physician or the consulting physician, a patient may be suffering from any psychiatric or psychological condition ~~including, but not limited to, depression,~~ that is causing impaired judgment, either ~~the attending or consulting~~ physician shall refer the patient for counseling to determine whether the patient is capable ~~competent~~ to request aid in dying.

(b) An attending physician shall not provide the patient aid in dying until the person licensed mental healthcare provider providing such counseling determines that the patient is not suffering a psychiatric or psychological condition ~~including, but not limited to, depression,~~ that is causing impaired judgment.

Sec. 13. (NEW) (Effective October 1, 2018) (a) As used in this section, "participate in the provision of medication" means to perform the duties of an attending physician or consulting physician, ~~a psychiatrist, psychologist~~ licensed mental healthcare provider, or pharmacist in accordance with the provisions of sections 2 to 10, inclusive, of this act.

The bill allows facilities to impose their beliefs on patients by restricting healthcare providers from participating in the practice of medical aid in dying.

As written, HB 05417 includes explicit provisions that allow healthcare systems to prohibit doctors from practicing medical aid in dying, thereby limiting access to this end of life care options and leaving individual physicians open to medical malpractice.

HB 05417 already ensures that participation in the practice of medical aid in dying is voluntary for individual providers as well as for patients. No provider can be forced to offer the service, and no patient can be forced to utilize the option. However, allowing a facility to pick and choose which end-of-life care services they offer or providers can discuss with patients prevents individuals from making an informed decision about their preferred course of treatment, which is contrary to the standard of medical care and leaves providers subject to liability including medical malpractice.

Patients have the right to make informed decisions based on their own deeply held values and beliefs, without fear of moral condemnation or political interference imposed on them by a medical facility. A facility's beliefs should never supersede the patient's and a dying patient should not be subject to subtle or overt suggestions that their choices are wrong or immoral.

Compassion & Choices strongly prefers that medical aid-in-dying legislation does not include explicit provisions that allow healthcare system to prohibit doctors from practicing aid in dying however, we recognize that including these provisions in legislation may address concerns that healthcare systems and their providers could be forced to participate against their personal

values. For the purposes of negotiating support for authorization of medical aid in dying, Compassion & Choices would not oppose limited facility prohibitions like those found in the Vermont and Colorado laws as well as the Compassion & Choices Model Medical Aid-in-Dying Bill, demonstrated below.

Healthcare facility permissible prohibitions.

(1) A healthcare facility may not prohibit a physician employed or under contract from providing medical aid in dying for a qualified individual unless the qualified individual intends to self-administer the medical aid-in-dying medication on the facility's premises.

(2) The healthcare facility must notify individuals and physicians in writing if it intends to prohibit physicians from writing medical aid-in-dying prescriptions for qualified individuals who intend to self-administer on the facility's premises, and refer the individual to a new healthcare facility without such a prohibition.

(i) If the individual wishes to transfer care to a new the healthcare facility, the healthcare providers will coordinate a timely transfer, including transfer of the individual's medical records.

(ii) A healthcare facility that fails to provide advance notice in writing to patients and physicians shall not be entitled to enforce such a policy against a physician.

(3) A healthcare facility or healthcare provider may not prohibit a healthcare provider from providing services consistent with the applicable standard of medical care including:

(i) informing and providing information to individuals about medical aid in dying.

(ii) being present when a qualified individual self-administers medical aid-in-dying medication if requested by the terminally ill individual or their representative; and

(iii) providing a referral to another physician.

Opportunities for Improvement

The bill contains some outdated and/or inappropriately used language.

Section 1 contains the following definitions, which Compassion & Choices would suggest be refined. Newly proposed language is underlined, language suggested for removal is ~~struck through~~.

(3) "Attending physician" means ~~the physician~~ a person who is authorized to practice medicine or osteopathic medicine, who has primary responsibility for the medical care of a patient and treatment of a patient's terminal illness; and who provides medical care to patients with advanced and terminal illnesses in the normal course of their medical practice. The attending physician's treatment may not be limited to or primarily comprised of medical aid in dying.

The suggested amendments are slightly more prescriptive than what is currently contained within the bill. The new language requires specific licensure to practice medicine in the state, ensures that the attending provider have the experience necessary to treat the terminally ill patient's disease without specifying any particular speciality, and establishes that physicians may not create a practice in which medical aid in dying is the only end-of-life care option they are willing or able to provide for their terminally ill patients.

(4) "~~Competent Mental Capacity~~" or "mentally capable" means, in the opinion of a patient's attending physician; and consulting physician, or mental healthcare professional if an opinion is requested under Section 8 ~~psychiatrist, psychologist or a court,~~ that a patient has the ability capacity to understand and acknowledge the nature and consequences of health care decisions, including the benefits and disadvantages of treatment, to make and communicate an informed decision ~~and to communicate such decision to a health care provider,~~ including communicating through a person familiar with a patient's manner of communicating;

Competency is a legal term referring to individuals "having sufficient ability... possessing the requisite natural or legal qualifications" to engage in a given endeavor. Unfortunately, this definition is too broad a concept and the definition, therefore, must be clarified to specify a terminally ill individual's ability to make an informed decision pertaining to end-of-life care options. The term "capacity" refers to an assessment of the individual's psychological abilities to form rational decisions, specifically the individual's ability to understand, appreciate, and manipulate information and form rational decisions, and is much more appropriate within the context of medical aid-in-dying legislation.

(6) "Counseling" means one or more consultations as necessary between a ~~psychiatrist or a psychologist~~ licensed mental health professional and a patient for the purpose of determining that a patient is ~~competent~~ mentally capable and not suffering from ~~depression or any other~~ psychiatric or psychological disorder ~~that causes~~ impaired judgment.

This amendment is consistent with the recommendation of expanding the scope of mental health professionals able to conduct a capability assessment to include licensed clinical social workers; and replacing the term "competent" with "mentally capable" as recommended above.

(9) "Informed decision" means a decision by a ~~qualified patient~~ terminally ill adult to request and obtain a prescription for medication that the ~~qualified patient~~ individual may self-administer ~~for aid in dying for a peaceful death,~~ that is based on an understanding and acknowledgment of the relevant facts and that is made after being fully informed by the attending physician of:

- (A) ~~The qualified patient's~~ individual's medical diagnosis and prognosis;
- (B) ~~†~~ The potential risks associated with self-administering the medication to be dispensed or prescribed for aid in dying;
- (C) ~~†~~ The probable result of taking the medication to be dispensed or prescribed for aid in dying; and
- (D) The choices available to the individual that demonstrate his or her self determination, including the possibility that they may choose not to fill the prescription for the medication, or may fill the prescription for the medication but may decide not to self-administer it; and
- (DE) ~~†~~ The feasible alternative,s to aid in dying and health care treatment options, concurrent or additional treatment opportunities, including, but not limited to comfort care, palliative care, hospice care and pain control.

Compassion & Choices supports informed healthcare decision-making that ensure thoughtful choices. As such, terminally ill individuals should be educated on all available end-of-life care

options and must not be given the impression that they are required to choose one over another. For example, as written the bill poses palliative care as an alternative to medical aid in dying when in fact, medical aid in dying is one option on the palliative care spectrum. There is no prohibition that a terminally ill patient requesting palliative care or hospice services is unable to also request medical aid in dying. This framing is necessary to ensure integration of medical aid in dying into the standard of care in the state of Connecticut.

(18) "Self-administer" means a qualified patient's affirmative, conscious, and voluntary act of to take into his or her body aid-in-dying medication to bring about a peaceful death. ~~ingesting medication;~~

By specifically stating "ingesting" in the definition of self-administer the law would limit the possibility of other routes of self-administration. The priority and emphasis should be affirming that it is the decision of the patient, and only the patient, to self-administer the aid-in-dying medication.

Sec. 9.

(6)(A) Dispense such medication, including ancillary medication intended to facilitate the desired effect to minimize the qualified patient's discomfort, if the attending physician is authorized to dispense such medication, to the qualified patient; or (B) upon the qualified patient's request and with the qualified patient's ~~written~~ consent (i) contact a pharmacist and inform the pharmacist of the prescription, and (ii) personally deliver the written prescription, by mail, facsimile or electronic transmission to the pharmacist, who shall dispense such medications directly to the qualified patient, the attending physician or an expressly identified agent of the qualified patient, or, with a signature required on delivery, by mail service or by messenger service.

Terminally ill individuals requesting medical aid in dying are already required to make three separate requests in order to obtain the prescription. Mandating an additional written consent to transmit a prescription to a pharmacy so that it may be filled is an antiquated requirement. This artifact of the Oregon law no longer serves a purpose.

Additionally, Compassion & Choices suggests adding a provision that would explicitly allow a prescription to be delivered to a patient via mail service or by messenger service. This is consistent with the way the vast majority of hospice medications are delivered to terminally ill patients. Mailing prescriptions is only allowed by entities that are registered with the DEA, and the most common medications prescribed for aid in dying are Schedule II prescriptions, which must be signed for upon receipt. This would reduce the burden on a qualified terminally ill individual ready to receive his or her aid-in-dying medication, especially in rural communities where the population already faces barriers to access to care, including proximity to a pharmacy.

Conclusion

Decisions about death belong to the dying, and good policy allows them to have an open conversation with their doctors, their loved ones, and their faith leaders about their physical and spiritual needs at the end of life. Without this law, doctors and family members risk prosecution from the state for attempts to fully discuss and enable all medical options at the end of life.

Again, we applaud the introduction of this important legislation and appreciate the opportunity to offer our expertise as the leading national non-profit dedicated to expanding choice at the end of life. We trust that the concerns we have shared with the Committee will be addressed and the bill will be amended appropriately, at which time we will be pleased to offer our full support.

Thank you again, Chair and Members of the Committee, for your timely leadership on this important issue.

Ashley Cardenas is the Policy & Programs Director for Compassion & Choices.

657 220 2402 [mobile](tel:6572202402)

800 247 7421 [main](tel:8002477421)

acardenas@compassionandchoices.org

www.compassionandchoices.org