

Written Testimony in Support of H7100: an Act Relating to Health and Safety - Lila Manfield Sapinsley Compassionate Care Act, Melissa Stacy, Regional Advocacy Manager, Compassion & Choices and Compassion & Choices Action Network Committee on Judiciary February 15, 2024 4 p.m. Eastern

Chair Craven and members of the Committee on Judiciary:

My name is Melissa Stacy. I am the Regional Advocacy Manager for Compassion & Choices. We are the nation's oldest and largest nonprofit organization working to improve care and expand options at life's end. We advocate for legislation to improve the quality of care for terminally ill patients and affirm their right to determine their own medical treatment options as they near the end of life. I am submitting this testimony in support of H7100: *An Act Relating to Health and Safety - Lila Manfield Sapinsley Compassionate Care Act*.

In a growing number of jurisdictions, lawmakers like yourselves are examining the experience of the eleven other jurisdictions that have authorized this medical practice and developing legislative approaches to meet the needs of their constituents who want the peace of mind that authorizing this law results in.

If passed, H7100 would allow mentally capable, terminally ill adults with 6 months or less to live the option to request, obtain and take medication — should they choose — to die peacefully in their sleep if their suffering becomes unbearable. H7100 includes strict eligibility criteria and practice requirements to ensure the highest standard of care. Patients can change their mind about utilizing the option at any time during the multi-step process. Participation is voluntary for patients and providers. It is important to note that individuals are not eligible for medical aid in dying solely because of advanced age, disability or chronic health conditions.

This option is *not* taken lightly and the many safeguards in place ensure that the decision is not made in haste. The multi-step request process is robust, the eligibility requirements are clear on who may qualify, and how individuals may obtain the medication under this law. The many safeguards have proven to work over the past 25 years in 11 authorized jurisdictions.

We all have our personal ideals, values, and ethics. Our last days and death should also be guided by these principles. Terminally ill people who are eligible under this act are dying. They deserve access to the full breadth of legal end-of-life options including the right to choose curative or life-extending interventions, or to forgo treatments and opt for palliative care, hospice care or medical aid in dying.

In an effort to ensure that the best possible legislation is passed, we have a few recommended changes to make the bill stronger. They are:

- 1. Add a definition of "self-administration," and refer to the term in certain sections of the bill.
 - a. The current bill does not define "self-administration," which is crucial to show patient self-determination, informed consent, and ensures that the patient takes the medication themselves. The self-administration requirement is one of the core patient safeguards to prevent coercion, and the jurisdictions where medical aid in dying is currently authorized all require that medication be self-ingested. Self-administration must be defined to say the medication must be ingested by the qualified patient, and does not include injection or infusion of the aid-in-dying medication. The proposed change also makes it clear that the medication cannot be administered, even by the patient themselves, via injection, infusion, or any other parenteral route. Parenteral route means administration outside of the digestive tract including intravenous, intramuscular and subcutaneous administration.¹

<u>Recommendation</u>: Add the following definition to Section 23-4.15-2.:

(o) "Self-administer" means a qualified individual performs an affirmative, conscious, voluntary act to ingest medication prescribed pursuant to this Act to bring about the individual's peaceful death. Self-administration does not include administration by parenteral injection or infusion.

- 2. Replace definition of "bona-fide physician-patient relationship" with "attending provider" and "consulting provider."
 - a. As written, the bona-fide physician-patient relationship includes both the "attending" and "consulting" physician. It also requires that a "personal physical examination is completed." It is not clear if a "personal physical examination" can be done via telehealth.

<u>Recommendation</u>: Replace "bona-fide physician-patient relationship" with the following: "Attending provider" means the provider who has primary responsibility for the care of the patient and treatment of the patient's terminal disease.

"Consulting provider" means a provider who is qualified by specialty or experience to make a professional diagnosis and prognosis regarding the individual's disease.

¹ Cambridge University Press, "Medication Safety: An Essential Guide, Chapter 7: Parenteral Administration." January 22, 2011. Available at:

https://www.cambridge.org/core/books/abs/medication-safety/parenteral-drug-administration/B00E3CE 7C00873D4114AA08E8B92DD86.

Not all patients who obtain a prescription will actually ingest the medication. Data from authorized jurisdictions shows that up to 37% of people who request the mediation may never take it. They derive peace of mind simply from knowing they have the option if their suffering becomes too great.² Additionally, in the over 25 years since the Oregon law was enacted, there has never been a single substantiated case of abuse or coercion of the laws. Instead, terminally ill people in these jurisdictions have been given the peace of mind to know that they have access to this option.

The data from the jurisdictions that have authorized medical aid in dying and subsequently published statistical reports demonstrates that less than 1% of people who die annually in an authorized jurisdiction will decide to use the law.³ However, awareness of the law has a palliative effect, relieving worry about end-of-life suffering. Individuals report experiencing enormous relief from the moment they obtained the prescription because it alleviated their fears of suffering.⁴ Quite simply, medical aid in dying is a prescription for peace of mind.

Researchers and legal scholars have confirmed that the experience across the authorized jurisdictions "puts to rest most of the arguments that opponents of authorization have made — or at least those that can be settled by empirical data. The most relevant data — namely, those relating to the traditional and more contemporary concerns that opponents of legalization have expressed — do not support and, in fact, dispel the concerns of opponents."⁵

The evidence is clear: medical aid-in-dying laws protect terminally ill individuals, while giving them a compassionate option to die peacefully and ensuring appropriate support and legal protection for the care providers who practice this patient-driven medicine.

Decisions about death belong to the dying, and good public policy enables them to engage in open conversations with their healthcare providers, their loved ones, and their faith or spiritual leaders about their physical and spiritual needs at the end of life. This legislation gives terminally ill people peace of mind to focus on the time that they have left. Terminally ill individuals don't have the luxury of endless deliberations; they need the relief that this law

² Medical Aid-in-Dying Data Across Authorized States, 2024. Compassion & Choices. Available from: https://www.compassionandchoices.org/docs/default-source/default-document-library/final_maid-utilization-report_ 1-24-2024.pdf?sfvrsn=5a81525d_2

³ Id.

⁴ A Therapeutic Death: A Look at Oregon's Law. Psychology, Public Policy, and Law, K. Cerminara & A. Perez, (2000) Available from: <u>https://www.ncbi.nlm.nih.gov/pubmed/12661538</u>

⁵ A History of the Law of Assisted Dying in the United States. SMU Law Review, A. Meisel, (2019) Available from: https://scholar.smu.edu/cgi/viewcontent.cgi?article=4837&context=smulr

affords them right now. Not a single additional person will die if this legislation is enacted, but fewer will suffer.

You will hear and receive testimony from patients and surviving family members about the importance of ensuring access to the full breadth of legal end-of-life options including the right to choose curative or life-extending interventions, or to forgo treatments and opt for palliative care, hospice care or medical aid in dying. I urge you to act now, because for many residents of Rhode Island, it is already too late. Not a single additional person will die if this legislation is enacted, but fewer will suffer. Rhode Island can realize these benefits for terminally ill people and their families right now by joining the growing number of jurisdictions that authorize this end-of-life option.

Thank you, Melissa Stacy Regional Advocacy Manager, Northeast 508-893-1687 <u>mstacy@compassionandchoices.org</u> <u>https://www.compassionandchoices.org/in-your-state/rhode-island</u>