Testimony Before Senate Health and Welfare Committee
January 12, 2022
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Good morning and thank you for the opportunity to testify on improvements to Vermont's Patient Choice at End of Life law, Act 39.

My name is Betsy Walkerman. I live in Underhill, Vermont and I am President of Patient Choices Vermont. I am a lawyer, having spent a long career working in both the for-profit and non-profit worlds. I worked with my parents Dick and Ginny Walters to launch Patient Choices Vermont (PCV) twenty years ago in 2002. After the passage of Act 39 in 2013, we established the organization as an educational non-profit focused on informing Vermont residents and the medical and care-giving communities about end-of-life choice.

PCV volunteers:

- Field 6-10 calls per month from patients and doctors
- Connect doctors who are new to aid in dying with knowledgeable colleagues
- Trained more than 2,000 people since Act 39 was passed and
- Created an extensive website including videos of Vermonters who have used medical aid in dying.

Act 39 has made a huge difference for people living with a terminal illness. There's a real person and a real family behind every one of the 116 people who have filed for aid in dying in the state, and there's a heartfelt story behind every note of gratitude that we receive. Pictures of some of these people are on the video that we sent to the committee.

Please take 5 minutes to watch the video of Karen Oelschlaeger, a young cancer patient, to understand more directly how people come to the decision to use aid in dying.
https://www.youtube.com/watch?v=GT5DrSCkJ3E&t=282s

When Act 39 was finalized in 2013, legislators placed great weight on preventing improper use of the law, so the process includes five qualification requirements, an eight-step procedure and full documentation. Every person qualifying for aid in dying must be diagnosed by two doctors as having a terminal illness with six months or less to live and they must be capable of making their own medical decisions. Participation in the law is completely voluntary.

Vermont now has experienced doctors, hospice nurses, and an excellent compounding pharmacy in Rutland that fills and delivers prescriptions. In parallel, hospice use in Vermont increased 26% since 2013, so that almost half of the people dying in Vermont are using hospice services.
(Source: https://legislature.vermont.gov/assets/Legislative-Reports/Deaths-and-Hospice-Care-Report.September-2021.Final.pdf)

Medical aid in dying is much more established across the country than it was in 2013. Today Vermont is among eleven states that have similar laws covering 22% of Americans.

In Vermont we now have eight years of experience. At PCV we have not received a single report of suspected abuse. Yet we do know how onerous the process is for dying people. It's time to strike a better balance, consistent with best practice across the country. Senate bill 74 was introduced in February 2021 to make three important adjustments to the law.

First, S.74 would remove the requirement that requests for aid in dying be in the physical presence of the doctor. Doctors would then follow existing law and practice on the use of tele-medicine in deciding whether they can make the required determination under Act 39. Note that Vermont is the only state in which requests for aid in dying have to be made in the physical presence of the doctor. See the comparison table of state MAID laws. Karen Oelschlaeger's video illustrates the need for this change.

Second, S.74 would fix a technical error in Act 39, which currently provides explicit legal immunity only for the doctors involved in the process. The amendment would clarify that all parties acting in accordance with the law would be free from claims of liability.

Pharmacists in particular have been reluctant to participate because of this defect. The principal pharmacist who fills Act 39 prescriptions requires doctors to sign an onerous indemnification agreement prior to filling a prescription. This reduces the number of physicians who are willing to prescribe and creates pockets around the state where patients have trouble finding a doctor who will prescribe aid in dying. All other state laws covering medical aid in dying provide immunity for all persons who comply in good faith with the law. See table of state laws.

Third, S.74 would adjust the steps required to get a prescription. The proposed amendment keeps the mandated 15-day period between the two oral requests. It keeps the requirement for two doctors and for a written request, but removes an unnecessary and burdensome additional 48-hour delay after the last step in the process, before a prescription can be written. 48 hours may not seem like much, but to a severely ill patient who must be able to self-administer the medication, it can make all the difference. Vermont's Act 39 timeline is one of the longest among the 11 jurisdictions that have MAID laws.

We recorded the story of Dee Allen, who was declining quickly from a neuro-degenerative disease, in connection with how the 48 hours affected her. Please listen at https://www.youtube.com/watch?v=UxRDbaJmDcA

Her son, Duncan Allen-Burns, further explained:

> "That last 48 hours was a nightmare. After six weeks working through the process, in that last 48 hours, there were any number of things that could have rendered my mother ineligible to do this procedure. That was the most dread and anxiety and fragility that I've ever seen on my mother who was the strongest person I've ever met. The sheer emotional toll that it took on her when she was just waiting for what felt like arbitrary reasons even though everybody signed off."

Summary: Medical aid in dying is an important and powerful option in the spectrum of compassionate care toward the end of life. Experience to date proves that Act 39 works well to effectively promote sound decisions and prevent abuse while providing comfort and choice to people suffering with terminal illness. Experience also tells us that some parts of the process cause unnecessary delay and added suffering for many qualifying patients.

With the changes made under S.74, Act 39 would serve Vermonters more effectively, while remaining strong, safe and consistent with other state laws and medical best practices.

Thank you for your consideration.

Background Documents (previously submitted):

1. **Graphic Act 39 Flow Chart:** Illustrates the requirements for a patient to qualify and the steps that the patient and doctor must complete.

2. **Comparison Table of State MAID Laws:** Summarizes the provisions of the medical aid in dying laws in all 11 jurisdictions with comparisons to the provisions of S.74.

3. **Act 39 & S.74 One-page Summary**

4. **Vermont Department of Health:**
    a. The required Vermont Department of Health forms may be found at https://www.healthvermont.gov/systems/end-of-life-decisions/patient-choice-and-control-end-life
    b. The Department of Health's 2022 report on Act 39 may be found at https://legislature.vermont.gov/assets/Legislative-Reports/2022-Patient-Choice-Legislative-Report.Final.pdf

5. **Patient Choices Vermont Links:**
    a. S.74 Summary Video: https://www.youtube.com/watch?v=i8Ty85m_tBw
    b. Videos of Patients Dee Allen and Karen Oelschlaeger: Includes comments on why S.74 is needed. https://www.patientchoices.org/videos.html
    c. Home Page: Provides links to extensive resources. https://www.patientchoices.org/