I am writing to ask you to support the Lila Mansfield Sapinsley Compassionate Care Act (H7760) which allows for medical aid in dying in Rhode Island. It has been before you many times, and has not received sufficient support to move to a vote. I am imploring you to support this legislation.

I am a clinical neuropsychologist. I worked on the inpatient rehabilitation unit at Kent Hospital for 30 years, so I have a long history of working in healthcare. I am currently working in an outpatient neuropsychology private practice in East Providence and I am a Clinical Assistant Professor in the Department of Psychiatry and Human Behavior at Brown University's Warren Alpert Medical School. I am also a volunteer at the HopeHealth Hulitar Hospice Center in Providence, where every Tuesday morning my dog Otis and I sit by the bedside of dying patients, offering care and support to patients and their families. I am a very strong supporter of hospice. For most people with a terminal illness, it is their best option for a peaceful death.

Your committee will receive written testimony from Leigh Anne Hohlstein PhD, and her testimony will be read at the House hearing on 4/30/2026. Leigh Anne is my dearest friend and I am her healthcare proxy. Leigh Anne has bulbar onset ALS, diagnosed in July 2025 which has caused a rapid decline in speech, which is now unintelligible. Swallowing is increasingly compromised and she already has choking and gagging episodes. She will very likely get aspiration pneumonia, because she will not be able to keep food, liquid, and even her own saliva from getting into her lungs and causing infection. This will all continue to get worse and breathing trouble will follow. She will eventually have to be on some type of ventilator to help her breathe. Death from this illness comes after many medical crises over a long period of time. There is, of course, no cure for ALS and we have explored all medical avenues with truly wonderful doctors and healthcare providers in Boston and Rhode Island. Feeding tubes and artificial ventilation only prolong the inevitable in this relentless disease, and they are not compatible with quality of life. So, Leigh Anne and all who love her are left with the impending doom of what is coming our way.

"Dying is hard work." This is the saddest thing that Leigh Anne has said to me- well, she texted to me on a voice app because the friendliest and chattiest person on earth can no longer speak. She has had to close a thriving private practice on the East Side- where she treated countless patients with eating disorders over her 30 year career. She has had to make financial arrangements for her 23 and 26 year old children, move her 90 year old mother into assisted living, and make provisions for her mother's care after she dies. She has had to manage health insurance and disability issues, while seeing a wide variety of healthcare providers including neurologists, speech therapists, and palliative care and hospice providers. Dying really is hard work.

The work of dying is made harder by her complete lack of control over this disease and how the end will finally come. As she continues to decline, Leigh Anne would like have some degree of agency, some level of control, over how the end of her life will be. That loss of autonomy- the inability to control one's life to any degree- is one of the most difficult parts of having this terrible illness. Having the option of medical aid in dying would have provided immense comfort to her. It is probably hard for you to identify with this- not being in her circumstances- but having the healthcare option of medical aid in dying would bring so much comfort to patients with terminal illnesses like ALS, whether they decide to use the option or not. Not having access to this option is an injustice to Leigh Anne, and creates an additional burden and anxiety. I don't want my friend to die. If there was anything in this world that I could do to prevent that, I would. But there isn't, so I am committed to making the end of her life as easy as possible, but the lack of this important healthcare option is taking away any control she could have had, and it is making a bad situation worse. Her only option at this point is to engage in Voluntary Stopping Eating and Drinking (VSED). In this protocol, patients who are capable of eating or drinking elect to stop doing so to hasten death. It is horrifying to me that she will need to resort to this option. Patients have every right to follow this path, but it is beyond sad to me that she will have to deprive herself of food and water, and suffer so that she has some control over her life. How can anyone make the case that this is a better option than medical aid in dying?

Opposition to medical aid in dying is generally framed as concern for others, the desire to "protect" vulnerable people such as the elderly or those with disability. I will assume this motivation is genuine, but it is wholly misplaced. The safeguards in the bill (outlined below) address the concern about protecting the vulnerable. Lack of medical aid in dying, however, is causing actual harm to Rhode Islanders like Leigh Anne, right now. This is not an imagined scenario- she is suffering because medical aid in dying is not available in Rhode Island.

Below are the provisions and safeguards in this bill, and a discussion of how medical aid in dying would work in Rhode Island, using Vermont as an example of how the program works successfully in a nearby state.

H7760 includes:

Eligibility:

- Adult (18+)
- Terminal illness, less than 6 months prognosis
- Mentally capable of providing informed consent

Provisions:

- Thorough review of **all end-of-life care options** by physician (hospice, palliative care)
- **The patient** must make 2 separate requests, with a 15-day waiting period between requests
- Evaluation by **2 physicians** certifying:1) prognosis 2) the decision is free of coercion, 3) the patient is mentally capable of making decision/can withdrawal from program at any time
- Medication must be self-administered
- Protection for **specialized healthcare providers** involved in the program
    - No healthcare provider can be required to participate

The above safeguards are in place to prevent any patient from being coerced to engage with this healthcare option. It cannot be requested by a third party for a patient and the patient has to be capable of fully cooperating with the process. Vermont has had medical aid in dying for 10 years. Almost 400 people have been through the program. Of those, 75% were prescribed the medication and used it, but 25% did not. I can tell you that those 25% who did not use the medication were greatly comforted by having access to it. In Vermont there have been **no credible reports of abuse** to the program to the Department of Health or the Attorney General's office. Vermont has allowed out of state residents into its program since 2023. In that time, **30%** of the people who went through the program were out of state (56/190). That means 56 people left their homes to die in another state in order to access the program, which is a heartbreaking statistic. There seems to be a misconception that if Rhode Island adopted this legislation it would lead to "death on demand", meaning a patient could go to their PCP, request medication, and go to CVS and pick it up. This is not what would happen. As in Vermont, specialized healthcare providers who wanted to be involved in the program could elect to see patients for evaluation. In the state of Vermont, there is only one pharmacy that dispenses the medication and it is very tightly regulated. Rhode Island could easily adopt this model, ensuring the safe use of this program.

If this bill passed tomorrow, it would be too late for Leigh Anne. Passage of the bill is one step in the process of medical aid in dying- the next would involve creating the healthcare structure that would support this healthcare option which would, and should, be done thoughtfully and will take a long time. As it is, we all, myself included, have failed Leigh Anne and patients like her by not attending to the very important issue of medical aid in dying in Rhode Island. Leigh Anne's hope is that passage of this bill will help those who inevitably come after her. That is my hope too. I never expected to be in this situation. I hope the options are better if you ever find yourself facing this situation with your husband, your wife, your sister, your brother, or your best friend.

Thank you for reading this lengthy testimonial. Please respect everyone's right to autonomy and support this bill.

Eileen G. Johnson, PhD
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