

Anabella Mayorga

From: Hohlstein, Leigh Anne <leigh_hohlstein@brown.edu>
Sent: Wednesday, April 29, 2026 10:38 AM
To: House Judiciary Committee
Cc: Rep. Kazarian, Katherine S.; Sen. Britto, Robert; Sen. Lawson, Valarie J
Subject: Support for H7760

Follow Up Flag: Follow up
Flag Status: Completed

You don't often get email from leigh_hohlstein@brown.edu. [Learn why this is important](#)

Chair McEntee and honorable members of the House Judiciary Committee:

My name is Leigh Anne Hohlstein and I am a resident of Rumford, RI. I am writing to ask for your support in passing the Lila Manfield Sapinsley Compassionate Care Act. I am a clinical assistant professor in the Department of Psychiatry, at Brown University's Warren Alpert Medical School. For the past 30 years I functioned as a clinical psychologist, with a busy private practice on the East Side of Providence. Last August, I had to close my practice because I was losing my ability to speak. I have long supported the ideas associated with this Compassionate Care legislation, but I now have a personal connection to the cause. I was diagnosed with ALS in July of 2025 and I am currently facing a terrifying and painful death from this illness. I would appreciate it if you could read my story and include it in your consideration of this important legislation.

My symptoms began in the spring of 2024 and culminated in the diagnosis of ALS in July of 2025. I have a variant of ALS called Progressive Bulbar Palsy. This form of the illness first affects the nerves controlling speech and swallowing, and then eventually moves to the limbs and other parts of the body. I am extremely fortunate to have an excellent team of doctors, both in Boston and Rhode Island. However, despite the full mobilization of my physicians, and all their recommended medications, the disease has marched on.

My symptoms have included a relentless cough, throat spasms that cause me to choke or gag, and a decreasing ability to swallow and control my mouth and tongue. This has led to an ever-shrinking range of foods that I can eat. At this point, I eat mostly soup and pureed food, and consequently, I'm slowly but consistently losing weight. Most difficult for me, in terms of quality of life, has been the loss of my ability to speak. Last spring, my speech was just barely slurred – most people still didn't notice. Now my speech is unintelligible.

Life with these ever-worsening symptoms is extremely challenging for me but I am managing. Facing death from this illness is another story. It is terrifying.

The most common causes of death from Progressive Bulbar Palsy are choking (saliva, as well as food can obstruct the airway); pneumonia, caused by aspirating food or liquid; and respiratory failure. Typically, death is preceded by multiple medical crises and hospitalizations

before something eventually proves to be fatal. It is hard for me to imagine enduring these crises, and impossible to imagine doing so repeatedly, and without the ability to communicate.

Knowing the likely realities of the late and end stages of my illness, it takes everything in my power to avoid succumbing to panic every day. The thought that initially brought me some comfort was the idea that Medical Aid in Dying (MAID) could be an option for me. While I know that my journey with ALS will be grueling, it was helpful for me to think that, when my pain and suffering got to be too great, I could have the option of an end to my life that was relatively peaceful. I am totally clear that I have no control over the fact that I am going to die from ALS. I just hoped that the end could be managed with a little more ease. Furthermore, I do not see the option of MAID as any form of threat to the sanctity of my life, or life in general, but instead, as an action that appreciates and respects the life that I have been given.

Ideally, I'd like to live the rest of my life and my final days, here at home, in Rhode Island. I'd like to be close to my children, family and friends, and keep my connection with my own team of doctors. Very unfortunately, I can't have the comfort of this final plan, as MAID is not currently a healthcare option in Rhode Island.

My friends and I thoroughly researched out of state MAID options, focusing in Vermont. While it is possible for me to take that path, the logistics involved, proved to be too challenging. This is, again, profoundly unfortunate for me, but it is important to recognize that part of what makes it hard for me to pursue MAID out of state, are the safeguards that surround the process., which I support. Medical Aid in Dying is not a process that is taken at all casually in Vermont or any other state. There are layers upon layers of protections that are built in to the system to prevent the abuse of this procedure. In Vermont, some of these safeguards include: requiring multiple doctors to verify the patient's diagnosis and nearness to death, and the requirement of several (at least three) appointments, across specified time periods, to make sure that the choice to pursue MAID is consistent and not coerced in any way. Also, there are strict controls around how the medication is prescribed and how it must be taken.

These types of safeguards are aimed at preventing MAID legislation from allowing for abuse of vulnerable populations or opening the door for any kind of normalization of suicide. In Vermont, only approximately 400 people have exercised this option since the MAID legislation was passed in 2013, and there have been no substantiated reports of abuse or coercion in connection with this practice to the Vermont Health Department and Attorney General's office.

Some are concerned that supporting MAID legislation threatens palliative and hospice care efforts and resources. This is not the case. In Vermont, the MAID process takes place in concert with Hospice services. Palliative and hospice care, and MAID options overlap and support each other. There is no need for one to take away from any other.

I am now under the care of Hope/Health Hospice here in Rhode Island, and am enormously appreciative of their services. Also, I am blessed to have a truly incredible support system of loving and capable friends and family. However, none of that can change the horrible realities of the end of this illness for me. While it is too late for me to benefit from the passage of the Lila Manfield Sapinsley Compassionate Care Act, I would hope that other terminal illness sufferers in Rhode Island, who come after me, could have this option. Thank you for your consideration and I hope that you support this very important legislation.

Sincerely, Leigh Anne Hohlstein



Me with my father in 2024

Leigh Anne Hohlstein, Ph.D.
Clinical Assistant Professor
Brown University
Warren Alpert Medical School
Department Of Psychiatry and Human Behavior
Providence, RI 02912
[\(401\) 374-4257](tel:(401)374-4257)