

February 11, 2025

Dear State of Rhode Island Judiciary Committee,

My name is Kira Philips, and I am writing to ask you to please support and pass H5219, *An Act Relating to Health and Safety– Lila Manfield Sapinsley Compassionate Care Act*.

I have been a passionate advocate for Medical Aid in Dying (MAID) for the past four years, after I lost my beloved mom, Clare Philips, to suicide on June 3, 2021. The prolonged and complex grief caused by the manner of her death has impacted me and my dad profoundly. Early that morning, my mom ended her life by shooting herself in the head, in the shed in our back yard. My dad, her husband of over 40 years, had to find her, an image he will never be able to forget. I was still asleep when he came running upstairs to tell me what had happened. Within 20 minutes there was a swarm of about ten police on our property, we were questioned by detectives, and they confiscated the letter she had left. In the coming days we had to hire a biohazard cleaning service and make arrangements for my mom with the funeral home, in which they told us there was “too much trauma” to do anything but cremation. My dad was shattered and has been left with functioning PTSD, anxiety, now has a psychiatrist, and sees a therapist. I lost my best friend, my hero, and my soul mate.

For some background, I was adopted as an infant, and my parents were some of the first Americans to travel to China to adopt unwanted baby girls in the early 1990's. This speaks to their selflessness, compassion, and kindness. I grew up in central Connecticut and have lived all over, including Cape Cod, Portland, OR, and Copenhagen, Denmark, but I now reside a little more than half a mile down the street in Smith Hill, where I bought my first home last year. Being raised by my parents is the greatest gift of my life, and I will forever be grateful for every opportunity I've been given thanks to them. My dad graduated from Yale and was a lawyer in Hartford for over 30 years, and my mom was born and raised in Connecticut and was a graphic designer for Hartford Hospital for the majority of her career. She was also a talented fine artist, and was very involved in the art community in Hartford. My mom was truly the most gentle and loving soul, hence why her firearm suicide was so utterly shocking.

My mom was diagnosed with Multiple Myeloma in 2018. She was being treated by oncologists at Dana Farber and Hartford Healthcare, but her diagnosis was tumultuous, in which she was in and out of hospice, had a period of remission, and then a quick decline. This period also coincided with the pandemic lockdown as well as the summer of 2020, when the country was experiencing political unrest after the murder of George Floyd. During the pandemic I moved from New London, CT back to my parents' home in Hartford, which is actually located directly behind the Governor's mansion (we literally share a property line). In the summer of 2020, the country was facing Black Lives Matter protests, Trump rallies, and mask mandate objections, as well as other events such as an uptick in Asian hate crimes. However, many of these protests were happening daily in our neighborhood. My parents had never owned a gun before, so when my mom told us she wanted to get a gun it was shockingly out of character. However, given the societal unrest at the time, it actually seemed valid. That summer, my mom was in remission and she obtained a gun permit, took shooting lessons, and legally bought a small firearm, of which she kept hidden in the basement and I never laid eyes on it. I now see clearly that her intention for getting a gun was not for protection, but to have it as a fast escape if her cancer progressed significantly, which it did by the beginning of 2021 when she stopped responding to treatment.

The Multiple Myeloma literally compacted my mom's spine causing her to shrink a half a foot in height. It also caused severe, radiating back and pelvic pain, making it difficult to walk and then stand. I recall more than once having to watch her crawl up the stairs to the bedroom. My mom endured a year– one whole year– of

relentless nausea from the chemotherapy, and although she did not lose her hair, she developed a golf ball-sized tumor that protruded from her scalp (not brain). She was just a shell of her former self and the rate at which she physically declined was scary.

On June 1, 2021 my mom and dad drove up to Dana Farber and she was offered one last treatment option. CAR-T Cell Therapy is a highly invasive blood and bone marrow transfusion that would have required my mom to be in-patient for a month, followed by six months of being in close proximity to the hospital in case there were complications. This means my mom would have had to not only endure this treatment but also rent an apartment in Boston for six months. The therapy could have potentially given her some more months or year(s) of remission, but it was not going to cure her cancer. She just did not have the strength to pursue it after what she had already been through with radiation and chemo. My mom and dad also discussed moving to Vermont to legally pursue MAID, but given her prognosis she did not have enough time to gain residency (six months), nor did she have the energy to get an apartment and establish a new medical team there. Today, Vermont is one of two states that has lifted the residency restriction, and my mom could have gone there and died peacefully.

No one deserves to get cancer. No one deserves to watch their loved one suffer and die horrifically. No one, especially my mom, deserves to die violently, alone, on the cold concrete floor of a dark shed. It is now my life's mission to ensure that no other family unnecessarily experience this kind of trauma. Medical Aid in Dying is the preventative mechanism. MAID not only prevents terminally ill people from suffering at the end of their life, but it prevents them from resorting to desperate, violent, and/or illegal methods. Additionally, it prevents having to watch a loved one suffer, and it prevents trauma. Public Health is about prevention, and I will be graduating with my Master of Public Health from Brown in August. I am fully committed to this work in honor of my mom. My home state of Connecticut disappointingly did not have a bill proposed in the 2024 legislative session, but in the past year I have focused my energy on education and research. I was able to present to three groups of students at Brown– the Brown Society of Bioethics and Health Humanities, the Brown Hospice Volunteer Organization, and undergraduate and masters students enrolled in Medical Sociology. I am also a research assistant for Dr. Elisa Kozlov, of Rutgers School of Public Health, and did data collection and abstraction of over 300 hospices' MAID policies in states where it is legal. Our paper was sent out for publication, and we are hoping it will be accepted soon.

The people of Rhode Island dying from terminal illness are at high risk of suffering. They deserve this right, if they so choose, and to deny them of it is an infringement of their respect for autonomy. For personal, moral, or religious reasons, there are probably very few qualified individuals who are actually interested in this option, even fewer will choose to pursue it, and even fewer will follow through with it and end their life with the medication. If the *Lila Manfield Sapinsley Compassionate Care Act* can save one person from dying like my mom, it will be worth it to spare a family from the trauma of losing a loved one to a shockingly horrible death. I am respectfully imploring you to please be the 11th state to legalize this end-of-life healthcare *option*.

Thank you so much for your time and consideration,

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My mom, dad, and me on vacation in the mid '90s