

VIEWPOINTS

My husband wanted to die at home. California denied him that right | Opinion

BY MARCIA HOFER SPECIAL TO THE SACRAMENTO BEE
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My husband, Ricardo, and I were lifelong planners. But when we faced our most difficult challenge, we discovered that under California law Ricardo couldn't plan how or when to end his life.

Ricardo began experiencing symptoms of dementia in the early 2000s. Having seen family members with dementia suffer catastrophic declines and given the ways his decline was impacting his capacity to do the things he loved most, Ricardo was determined to end his life before dementia robbed him of his dignity and his autonomy.

California's End of Life Option Act provides legal and peaceful medical aid in dying (MAID) to those who have a terminal diagnosis and are within six months of dying. But people suffering from dementia are barred from accessing MAID: they will lose the capacity to make decisions long before reaching that six-month point.

Ricardo wanted to pursue a legal way to die at home, but because he could not access MAID, we needed to find an alternative.

We considered our options, but none seemed viable. Some options could have even led to severe legal consequences. So Ricardo chose to have an assisted death in Switzerland, the only country in the world that offers this choice to non-citizens. The months before his death were spent saying goodbye to family and friends — a moving experience for all who participated.

Our family traveled to Switzerland, where Ricardo died at the Pegasos clinic on October 1, 2021. After turning a dial that released a lethal medication into an IV in his wrist, he died within moments, surrounded by his closest loved ones and listening to his favorite music.

This was the painless and peaceful death he had hoped to have at home.

Nearly 75% of people who utilize MAID are suffering from terminal cancer. For these people, California provides the option of a compassionate death. But for those who suffer from dementia, California's law offers nothing. This effectively creates an underclass of patients who must either scramble for a solution or accept the inevitable decline that will be their fate.

The good death that Ricardo had is only available to people who have the financial means and physical stamina to travel to Switzerland. Many who would choose this option cannot do so. For these reasons, I and several others formed A Better Exit, with the goal for California to remedy the inequities in current law so that all people with terminal illnesses have access to MAID.

On the morning of his death, Ricardo was interviewed at Pegasos. Here is some of what he said:

"I firmly believe that this is a right that every human has, to determine when and how to leave this life. I'm not committing suicide. I am committing to live my life to its very very end with the same kind of values I've tried to exercise throughout my life. I hope that there will come a day when dying will be treated like any other human experience, rather than something that has to be avoided at all costs. It cannot be avoided, because we all are destined to die. The issue is how we die, and with what kind of values."

Everyone should have the option to die on their own terms and have meaningful goodbyes with friends and family. According to the California Department of Public Health, the number of Californians living with dementia will reach over 2.1 million by 2040. If you are one of them, will you want the right to have the good death that Ricardo had in your own home?

Marcia Hofer, Ph.D. is a retired clinical psychologist and a reluctant activist who became the founding president of A Better Exit after the death of her husband. For more information, visit www.abetterexit.org.



The author's husband. Marcia Hofer