

60 REASONS TO SUPPORT NEW YORK'S MEDICAL AID IN DYING ACT

Ronald Thomas

Watched his husband, William Stubing, die
without access to medical aid in dying

New York, New York



Reason #50

So the last moments of a loved one's life can be spent embracing them.

William Stubing could plan and execute the perfect dinner, celebration, or vacation. Watching Bill put together such an event was watching an artist at work. Christmas was a familiar composition with a tree, cakes, cookies, and his father's eggnog recipe. Christmas 2014 was carefully executed but smaller because of the great pain he endured. On Christmas Eve after midnight mass, he told me what he was putting together for 2015. He was planning to end his life.

This is the story of what happened to those plans and how Bill lived his last year. It is also a tribute to his humanity, love, and wisdom. He had a design for living that I and many were the beneficiaries of. He also had a design for dying.

We had talked about medical aid in dying and agreed that it was a legitimate decision for someone with a terminal diagnosis. Legitimate, but not legal in most states, including ours. Bill had looked into various possibilities — we could move or he could look at other options. He preferred to stay in New York and die at home. I told him I would support his decision as long as it was legal.

By 2014, he had been suffering for a long time. He had tried medications, acupuncture, epidurals, physical therapy. His doctors suggested spinal fusion. Bill didn't know what the outcome of surgery would be. What he did know was constant pain and constant failure of everything he tried. Although I was in favor of trying surgery, he decided it was too risky. He would try palliative care, and if the medicine couldn't help with the pain, he wanted medication to help with his death.

During a hospital visit in September 2015, the palliative care doctor took me aside and told me that Bill's condition was terminal. He returned home with hospice care. This lasted only four days.

By October 4 his breathing had become heavier and louder. As the home health aide and I were looking at the dropper for the morphine, we heard a sound. We turned and saw Bill's head lifted off the pillow, and he was looking toward us, making a clicking sound. And then nothing. His head fell back, and it was over. Had Bill been trying to get my attention? Did he know he was about to die and wanted me by his side, holding his hand? Was it just a reflex reaction of death? For my own sanity, I try to pretend it was just a reaction that didn't mean anything.

It's hard to push the thought aside. If he was trying to get my attention when he died, what torture. Your loved one is in the room. You want him by your side, but he's looking the other way. Five feet is all that separated us. But it was an untraversable chasm. He died alone. This wasn't the death he wanted or deserved.

An argument against medical aid-in-dying legislation is that family members or others will coerce a patient into accepting medical aid in dying when the patient doesn't want it. I think most family members are like me. If they err, they err on the side of wanting their loved one to stay with them. If I coerced Bill, I coerced him to try whatever it took to keep living. My love for Bill was a selfish one that didn't want to let him go, even when his wishes were very clear and his misery and decline were obvious. The Medical Aid in Dying Act has safeguards to ensure that the patient is not coerced to choose dying. There are no laws that provide safeguards so a patient is not coerced to choose living at all costs.

For those who oppose aid in dying, the end of Bill's life may seem like palliative care as it was meant to be. Or at least as it was meant to seem. We can't pretend drug-induced calm is normal living or that it's living as the patient would want. When the patient can't communicate, we simply don't know. These drugs seem to work wonders. But what are they like from the patient's perspective? Are we just keeping the patient quiet for our peace of mind? The best we can do is try to follow what the patient wanted when they could communicate.

Palliative care is right for some patients. Medical aid-in-dying is right for other patients. Bill and I had many conversations about aid in dying, and he would not only approve of my advocating for the Medical Aid in Dying Act on his behalf, he would have wanted me to.

William C. Stubing was President Emeritus of the Greenwall Foundation. He served as a priest and worked at the American Medical Association, and then the New York Academy of Medicine, as Director of the Academy, the first and only non-physician to hold that position.

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