

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

Bonnie Rose Marcus

Her fiancé, 9/11 first responder Jay Kallio, was not able to die in accordance with his values.

Brooklyn, New York



Reason #34

So that no one has to die in agony despite receiving world-class palliative care at a top NYC hospital.

Jay Kallio's life was more vibrant than any life I've ever known, and we loved each other deeply. Although we knew his time was limited, he had a dedicated oncologist and highly supportive palliative care and pain management team who worked with him to try to make his quality of life the best it could be.

Jay was very astute about his condition and the available treatments. He talked to his doctor like he was part of the medical team. He was eventually able to receive immune therapy treatments, which did give him an additional few good months. We lived each day fully, whether he was in or out of the hospital. We were each other's greatest gift.

A few weeks before he died, Jay lost the ability to feel or move his legs and was unable to urinate without a tube. But his spirit was energetic and vibrant as ever.

He wanted to live as long as he could, so we could be together. We planned his stay in hospice, feeling like there could be months, maybe six, or even a year, despite his dire prognosis.

On a Friday at 2 a.m. I got a text from Jay. I had gone home to rest after spending many hours day-after-day in the hospital with him. He was in extreme pain and being moved to the oncology unit. When I got to the hospital, Jay was crying out loud in pain. For the next 17 hours, teams of doctors and nurses, from pain management to palliative care to oncology doctors came in and out of the room. No one was able to relieve his pain.

Let me tell you this about Jay. He was someone with high endurance for pain, if he said his pain was 6 or 7, on a scale of 1 to 10, he was doing great. At that point, Jay was screaming out loud, "Oh, God please stop this, stop this pain!"

No one had an answer and one could do anything to relieve the pain. At one point, they were asking Jay if he knew where he was and could understand them. He was very cognizant, although it was difficult for him to talk because of the pain.

He was very clear that he did not want to be put through any unnecessary procedures, he just wanted to be out of the horrific pain.

They said they wanted to do a CAT scan to determine what area the pain was affecting when it was clear according to Jay it was in his abdomen. We both said no to that. They finally came to the conclusion it was probably an infection and really there was nothing to be done, and they had no solution for his pain.

Jay was receiving good quality health care and was a strong advocate on his own behalf. But at this moment when he really needed relief, no one on the medical team had a solution. Jay had always wanted me to be with him at the time of his death, but this is not how we imagined it.

We thought it would be a peaceful death, because so much care had been taken with dealing with his cancer. But instead, he was in dire pain, and we could not even communicate with each other.

I could see a change in Jay's face, it became somewhat distorted. His eyes rolled back. His legs and feet were very swollen. Soon after, his vitals stopped, but his heart was still warm. I stayed with Jay for several hours. He was out of pain, but he was gone. All I could do was be with my love and pray and somehow control my deep sorrow until I was out of the hospital.

When I finally walked out into the night air, the tears poured out of me. I had lost the love of my life, my soul mate. And, he had just died a horrible painful death, which was his greatest fear. I hold many wonderful loving memories of Jay and me, but the memory of Jay's traumatic death stays with me, and it is deeply distressing.

Jay's legacy is that of someone who would fight to help anyone who was suffering. His life was one of service and compassion. He always fought for justice, for those who didn't have a voice, for those who were suffering — he was one of many first responders who ran to help on 9/11.

So with his death, his fight continues - to give human beings the dignity and choice to have a good death, of being cared for in the best possible way and most importantly to avoid unbearable pain. Going through and sharing this experience, I sincerely hope that we can make a commitment to caring for the dying with compassion and choices that allow for grace and dignity, as each of us and our loved ones face death.

I ask you to deeply reflect on this for yourself, and if you can find it in your heart, support this bill, so you and your loved ones don't have to suffer the great pain that my husband-to-be, Jay Kallio did at the end of his life.

**To join our mission, email Amanda Cavanaugh
at acavanaugh@compassionandchoices.org.**

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