

Killing with kindness: Why the Death With Dignity Act endangers people with disabilities

By **S.I. ROSENBAUM** | October 31, 2012

I think my opinions about doctor-assisted suicide crystallized the night Mike — my wheelchair-using, ventilator-breathing boyfriend — choked on pineapple juice, passed out, and died.

He was dead for several minutes, on a steel table in the ER. The doctor shocked the pulse back into his heart and dropped him into an induced coma, but it still wasn't clear whether he would make it. As I stood by his bedside, shaking, one of the nurses touched me on the shoulder.

"Maybe it's better this way," she murmured.

I'll never forget that moment. We'd been watching a movie together a few hours before. We had plans to go clubbing. *Maybe it's better this way?*

I'm not a violent person, but I wanted to punch that lady in the face.

When I started going out with Mike, I thought that prejudice against people with disabilities was something we'd left behind along with Jim Crow and sodomy laws. I was shocked, again and again, to find that I was wrong. So wrong. Everyone I met had ideas about what it must be like to date Mike — that we never went out, that we couldn't have sex, that I must have to take care of him all the time — that were so false as to be laughable. We did laugh at that stuff. We had to. But for every person who came up to us to congratulate Mike on his "bravery" in taking a trip to the mall, there was someone who actually thought he'd be better off dead.

Some of those people were doctors.

Not the young doctor who fought like a demon to restart his heart in the ER. But there were others: well-meaning doctors who saw Mike, and people like him, as pitiable — as "bad outcomes." In fact, that's the norm: study after study has shown that doctors, as a group, consistently underestimate the quality of life of their disabled patients. Those prejudices — unquestioned and unacknowledged — can have disastrous results.

I don't know anyone born with a serious disability whose doctors didn't tell their parents that they would never be able to live independently. A doctor at Mass General, who treats

children with muscular dystrophy, told me about colleagues who had counseled their patients against using the ventilators that would prolong their lives by decades. Those doctors weren't trying to do harm. They simply saw their patients' lives as not worth living.

As disability activist Carol Gill writes: "Many of us have been harmed significantly by medical professionals who knew little about our lives, who thought incurable functional impairments were the worst things that could happen to a person, and who were confident they knew best."

All this, then, is why I'll be voting against referendum Question 2, the Death with Dignity Act, on November 6.

The language of the bill sounds reasonable: it would allow doctors to prescribe lethal doses of medication, upon request, to patients with terminal diseases. But it wouldn't actually have much benefit for the dying, who already have the same access to self-administered suicide as anyone else. Instead, it could present doctors with an option to offer the patients they think they can't help: the bill's definition of "terminal disease" is so vague as to encompass disabilities like Mike's, and it has no requirement that a person seeking the fatal dose see a counselor or be screened for depression.

So why would a person with a disability ask for a suicide pill? My ex never would. Disabled from birth, Mike has been fighting for his rights since he was in grade school. He's a badass with 60 tattoos, and he's not ready to die any time soon.

But for the late-disabled, it's different. People diagnosed with a progressive disease — MS, ALS, and other such dire acronyms — still carry the same prejudices they've held all their able-bodied lives. Often, they don't know anyone living a full, enjoyable life with disabilities, don't know such lives are possible. So if a doctor offers them an exit, they're all too likely to take it.

It's happened. One of the earliest right-to-die cases, in 1989, was that of David Rivlin, a spinal-cord-injury survivor. Isolated in a nursing home, cut off from meaningful work, unable to live independently on the meager assistance the state offered at the time, he demanded to die. "I don't want to live an empty life lying helplessly in a nursing home for another 30 years," he told a reporter.

No one offered him an alternative. "The nondisabled people around him assumed that when a person with such a disability said he would rather be dead, he was acting rationally," disability activist Paul K. Longmore wrote a few years after Rivlin's death. Neither Rivlin, nor other people with disabilities seeking "death with dignity," realized that they could have been fighting for the support to live, rather than the right to die. Longmore

observed, "The only real aid the system offered any of them . . . was assistance in ending their lives."

It's not 1989 anymore. The disabled in Massachusetts have more access, and more agency, than those in almost any other state, and activists fought hard to make it that way. Disabled Bostonians are filmmakers, tattoo artists, psychologists, writers. They ride the T. They own houses and businesses. And like Mike and me, they fall in love.

But not everyone knows that those things are an option. And with Romney — a man who sees adequate health care as a privilege, not a right — on the same ballot as Question 2, all that progress is scarily close to rolling back. Now is the worst time to perpetuate the myth that death is better than disability.

Vote no on Question 2.

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