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Suicide by Choice? Not So Fast

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NEXT week, voters in Massachusetts will decide whether to adopt an assisted-suicide law. As a good pro-choice liberal, I ought to support the effort. But as a lifelong disabled person, I cannot.

There are solid arguments in favor. No one will be coerced into taking a poison pill, supporters insist. The “right to die” will apply only to those with six months to live or less. Doctors will take into account the possibility of depression. There is no slippery slope.

Fair enough, but I remain skeptical. There’s been scant evidence of abuse so far in Oregon, Washington and Montana, the three states where physician-assisted death is already legal, but abuse — whether spousal, child or elder — is notoriously underreported, and evidence is difficult to come by. What’s more, Massachusetts registered nearly 20,000 cases of elder abuse in 2010 alone.

My problem, ultimately, is this: I’ve lived so close to death for so long that I know how thin and porous the border between coercion and free choice is, how easy it is for someone to inadvertently influence you to feel devalued and hopeless — to pressure you ever so slightly but decidedly into being “reasonable,” to unburdening others, to “letting go.”

Perhaps, as advocates contend, you can’t understand why anyone would push for assisted-suicide legislation until you’ve seen a loved one suffer. But you also can’t truly conceive of the many subtle forces — invariably well meaning, kindhearted, even gentle, yet as persuasive as a tsunami — that emerge when your physical autonomy is hopelessly compromised.

I was born with a congenital neuromuscular weakness called spinal muscular atrophy. I’ve never walked or stood or had much use of my hands. Roughly half the babies who exhibit symptoms as I did don’t live past age 2. Not only did I survive, but the progression of my disease slowed dramatically when I was about 6 years old, astounding doctors. Today, at nearly 50, I’m a husband, father, journalist and author.

Yet I’m more fragile now than I was in infancy. No longer able to hold a pencil, I’m writing this with a voice-controlled computer. Every swallow of food, sometimes every breath, can become a battle. And a few years ago, when a surgical blunder put me into a coma from septic shock, the doctors seriously questioned whether it was worth trying to extend my life. My existence seemed pretty tenuous anyway, they figured. They didn’t know about my family, my career, my aspirations.

Fortunately, they asked my wife, who knows exactly how I feel. She convinced them to proceed “full code,” as she’s learned to say, to keep me alive using any and all means necessary.

From this I learned how easy it is to be perceived as someone whose quality of life is untenable, even or perhaps especially by doctors. Indeed, I hear it from them all the time — “How have you survived so long? Wow, you must put up with a lot!” — even during routine office visits, when

all I've asked for is an antibiotic for a sinus infection. Strangers don't treat me this way, but doctors feel entitled to render judgments and voice their opinions. To them, I suppose, I must represent a failure of their profession, which is shortsighted. I am more than my diagnosis and my prognosis.

This is but one of many invisible forces of coercion. Others include that certain look of exhaustion in a loved one's eyes, or the way nurses and friends sigh in your presence while you're zoned out in a hospital bed. All these can cast a dangerous cloud of depression upon even the most cheery of optimists, a situation clinicians might misread since, to them, it seems perfectly rational.

And in a sense, it is rational, given the dearth of alternatives. If nobody wants you at the party, why should you stay? Advocates of Death With Dignity laws who say that patients themselves should decide whether to live or die are fantasizing. Who chooses suicide in a vacuum? We are inexorably affected by our immediate environment. The deck is stacked.

Yes, that may sound paranoid. After all, the Massachusetts proposal calls for the lethal dose to be "self-administered," which it defines as the "patient's act of ingesting." You might wonder how that would apply to those who can't feed themselves — people like me. But as I understand the legislation, there is nothing to prevent the patient from designating just about anyone to feed them the poison pill. Indeed, there is no requirement for oversight of the ingestion at all; no one has to witness how and when the lethal drug is given. Which, to my mind, leaves even more room for abuse.

To be sure, there are noble intentions behind the "assisted death" proposals, but I can't help wondering why we're in such a hurry to ensure the right to die before we've done all we can to ensure that those of us with severe, untreatable, life-threatening conditions are given the same open-hearted welcome, the same open-minded respect and the same open-ended opportunities due everyone else.

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