Over My Dead Body

Leagalize assisted suicide? A disability-rights activist says no

January 1, 1998 By Kevin Irvine

People with AIDS tend to have a skewed view of legalizing physician-assisted suicide. We usually think about it only in terms of our own illness. We remember those who died from painful, debilitating diseases and infections, and this understandably makes some of us want a degree of control over the end of life. Living with both severe hemophilia and HIV, I had a similar view until I became an activist in the larger disability community. Since then I've come to believe that legalizing assisted suicide will have a devastating effect on how people with other, nonterminal disabilities, such as multiple sclerosis, cerebral palsy and muscular dystrophy, are treated by the heath care system.

Quality of life means one thing for someone who is 42 and has been battling full-blown AIDS for five years, and something entirely different for a 22-year-old with a spinal-cord injury who may live 60 more years. Making assisted suicide legal will let the PWA decide when enough is enough, but it will likely encourage the youth – who now, unable to afford the personal assistance needed to live independently at home, is forced into nursing home, who cannot get a job because of discrimination and who is viewed as an object of pity – in the belief that life is not worth living. Instead of fighting to make it easier for this 22-year-old to die, I think we should fight to make his or her life better – with adequate health care, home and community services, jobs, public transit, benefits – and role models who've successfully dealt with the same disability.

Not Dead Yet, a disability-rights action group, is deeply concerned about the dangers of legalizing assisted suicide. For over two years, the group has brought a different, previously unheard perspective to this debate. In doing so, we've found ourselves allied with some strange bedfellows, such as the AMA and "right to life" groups; unlike most of them, however, our motivation comes not from a religious belief in the sanctity of life but from someplace deeper: Fear. We fear that the discrimination faced every day by people with disabilities will lead to widespread abuse of assisted suicide (see "Supreme Indecision"). Many people – including our friends, family members and doctors – still think (and say out loud) that it would be better to be bead than disabled.

Since the Clinton administration abandoned the drive for universal health care system four years ago, mangled care has grown like cancer. My own HMO, owned by Cigna Corp., proposed a system to give cash rewards to doctors whose patients cost less and have fewer procedures. This bottom-line approach to medicine wrests control from physicians and consumers and cedes it to bean

counters. These are the values of the system into which we plan to introduce physician-assisted death, the ultimate money-saver. That thought scares me to my core.

My fears have taken root from seeds already planted in out current arrangements for dying. Patients entering hospitals, especially those with disabilities, are repeatedly urged to sign DNRs (Do Not Resuscitate orders, which allow the hospital to unilaterally avoid extensive life-preserving measures regardless of the emergency), even when under influence of narcotic medication or severe stress. Some hospitals have policies prohibiting life-saving procedures for people with certain disabilities. Many people – having never unlearned society's scorn of what life with disability is like – prepare living wills prior to any hospitalization. One woman who signed such a document had a stroke, wound up in the hospital partially paralyzed and decided she wanted to live. But the hospital refused her pleas for food and water, and she starved to death 10 days later.

Most doctors admit to having inadequate training in treating people with chronic disabilities and end-stage illness, especially in the proper management of pain and depression, which would lessen, if not prevent, much suffering. While some people with full-blown AIDS will not "get better", others wit nonterminal disabilities will have symptoms and life situations that wax and wane. One man with multiple sclerosis said he was seeking the so-called services of Dr. Jack Kevorkian to avoid having to go into "a rat-infested nursing home."

If assisted suicide were legal, for every person who will make a careful, reasoned decision to end his or her life, there will likely be those who act in haste, under pressure, when they feel their life is meaningless and a burden to others. And for those who view their doctors as close to a god and faithfully follow every treatment regimen, how powerful to hear a physician offering the possibility of a relatively painless death as a "solution" – a permanent one. It's worth recalling the grim climate in the AIDS community just three years ago, before the widespread use of protease combinations. Now, as I write this, the CDC has just announced that AIDS is no longer the No. 1 killer of adults aged 25 to 44. We all know people facing death sentence who've staged remarkable recoveries. Had a physician-assisted death been legal back when hope was scarce, some wouldn't be around today.

At a time when the fight against AIDS holds more promise than ever and yet our dreams of equality and justice are deferred, why do we waste energy fighting to grant our mangled medical system more power to get rid of us? To think we can control this genie once it's out of the bottle flies in the face of all evidence. I don't trust our society to handle assisted suicide any better than it has handled AIDS epidemic. I plead with my community to move beyond its skewed view and listen to all of the people who will be affected by physician-assisted suicide.

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