

Opposing The Legalisation Of Physician Assisted Suicide

This afternoon, I learned that author Sir Terry Pratchett supports physician assisted suicide, and further, offers himself as a test case. Sir Pratchett has Alzheimer's. His entire life flows from his imagination and his ability to think. I can well understand his fear, and even terror at the idea of losing it. If he wants to kill himself, that is, as far as I'm concerned, his right. But it is not sufficient to make it legal for physicians to help with killing people.

Not Entirely Black Nor Entirely White

I am fond to point out to people that nothing in life is either black or white. Shades of grey. It would be hypocritical of me to ignore that when talking of legalised physician assisted suicide. This is a rather complex and controversial issue. It inflames passions. I must disclose that I come to it from the point of view of a disability rights advocate. I must further disclose that I have participated in several protests against physician assisted suicide or people supporting it. I recognise that there are situations where the assistance of a physician is appropriate. It is the legalisation of said assistance I oppose.

I oppose the legalisation of physician assisted suicide.

I haven't always opposed it. But as I learned more about it, and the many layers of complications surrounding legal human euthanasia, I came to oppose it. Vehemently.

Autonomy

It used to be that I thought physician assisted suicide should be allowed in terminal cases of cancer, or other dire conditions. This appears to be a common feeling. It is a logical, and perhaps even humane feeling. @slyall just said on twitter: "Full 'Johnny got his gun' level would probably be in a majority", referring to the anti-war novel by Dalton Trumbo, in which a WW I soldier who lost both legs, arms and his face is left in a completely helpless situation. This soldier, Joe Bonham, manages to establish communication by moving his head against the pillow in some form of Morse code. He expresses his desire to be put in a glass box and paraded around the country to show people the true horrors of war. Yet, his wishes are ignored, and it is implied that he'll be stuck in bed for the rest of his life. I think @slyall didn't realise what a great example he brought to the table when mentioning 'Johnny got his gun'. It is a story that contains a lot of the issues at hand.

Once Joe managed to communicate, his expressed wish was not to be killed. He wished to be shown around to change the world (get people to understand the horrors of the war). He had a purpose. Despite what can easily be called a "dire condition", Joe found something he was passionate about and wanted to act on, and that was not dying. Yet, because he was dependent on other people, he was helpless. His desire to be displayed to the public is his expression of self-direction and autonomy. You may require other people's help in daily activities, but as long as your helpers follow your wishes, you are independent. Joe is not autonomous because his doctors are refusing to do what he wants. (Literary sticklers - I have simplified the plot!).

The loss of autonomy is often cited as a desire for death, whether it comes from people with disabilities or without. I've heard often enough that people "couldn't handle to have someone wipe their bums for them". These people speak of dignity. The lack of dignity comes from how people are (mis)treated. It's not so much *what* you do to people, as much as *how* you do it. Having people help you through tasks of daily living, intimate or not, is not degrading, if the helpers are caring and not demeaning.

Strong Controls

The one argument that I find difficult to contradict is cases of terminal illnesses where the person is in severe pain. I don't want people to suffer pointlessly. I wouldn't want to if it were me in that situation. Yet, it is not enough to legalise physician assisted suicide. Even with "strong controls", as @jethrocarr suggested, the idea of legalised physician assisted suicide scares the crap out of me.

Consider that it is illegal (most everywhere) for physicians to help people die. Further consider that physicians can, and *do* help people die, despite that action being illegal. How could strong controls possibly work, considering that an illegal act (technically murder) is already practiced often enough? What kind of controls would be appropriate and strong enough to ensure that only the "right" people got to off themselves with the assistance of their doctors? Who checks on those controls? Who determines the eligibility of an individual to receive assistance to die? Eventually a judgement call has to be made to take that decision. And because we're talking about dire medical condition, doctors would have to be involved in making that judgement call.

Medical Bias Against Disability

But I have a major issue with doctors making a judgement call on my quality of life. Several studies have shown that medical personnel have a negative bias against disabilities. The following numbers [1] blow my mind every time I read them:

- 86% of spinal cord injured high-level quadriplegics rated their quality of life as average or better than average. Only 17% of their ER doctors, nurses, and technicians thought they would have an average or better quality of life if they acquired quadriplegic (KA Gerhart et al., *Annals of Emergency Medicine*, 1994, vol. 23, 807-812).
- No differences were found between 190 physically disabled persons and 195 "able bodied" persons on ratings of life satisfaction, frustration with life or mood (P Cameron et al., *Journal of Consulting and Clinical Psychology*, 1973, vol. 41, 207-214).
- The duration of disability was positively related with acceptance of disability in persons with spinal cord injury-related paralysis. Severity of disability was of no importance in accepting life with a disability (F Woodrich & JB Patterson, *Journal of Rehabilitation*, 1983, July-Sept., 26-30).
- 60% of paraplegics reported feelings more positively about themselves since becoming disabled (C Ray & J West, *Paraplegia*, 1984, vol. 22, 75-86).

- Interviews and tests administered to 133 persons with severe mobility disabilities revealed no differences between them and the nondisabled norm on psychosocial measures. In another study, no significant difference was found between persons with severe disabilities (requiring wheelchair use and daily personal assistance) and persons with no disabilities on quality of life measures (R Stensman, Scandinavian Journal of Rehabilitation Medicine, 1985, vol. 17, 87-99).
- In a study of life satisfaction of quadriplegics, fewer than a third of those who used ventilators expressed dissatisfaction with their lives. There is evidence that life satisfaction scores are higher in persons who have had more time to adjust to disability (JR Bach & MC Tilton, Archives of Physical Medicine and Rehabilitation, 1994, vol. 75, 626-632).
- Spinal cord injured rehabilitation patients were similar to the general population on self-ratings of depression, yet hospital staff consistently overestimated the patients' level of depression (LA Cushman & MP Dijkers, Archives of Physical Medicine and Rehabilitation, 1990, vol. 71, 191-196).
- Three-quarters of persons with spinal cord injuries rated their quality of life as good or excellent. Amount of paralysis made no difference, but people who used ventilators rated their quality of life higher than those not needing ventilators (GG Whiteneck et al., Rocky Mountain Spinal Cord Injury System Report to the National Institute of Handicapped Research, 1985, 29-33).
- Elderly paralyzed veterans rated their quality of life higher than similarly aged men without disabilities (MG Eisenberg & CC Saltz, Paraplegia, 1991, vol. 29, 514-520).

So you're asking these individuals to decide if someone's life is worth living. They cannot be impartial. Whether they recognise it or not, they are biased towards end of life, as paradoxical as that may appear at first - they are doctors sworn to heal and help people live but... Similarly, when doctors advise families of injured individuals, it is too easy for them to convey the likely "low quality of life" of the patient once they stabilise. Families could easily chose to "pull the plug" on the biased advice of doctors. Yet that loved one might well have been able to live a full, autonomous life, had they been given the chance. I am reminded of so many cases of "locked in" syndrome where people who had been thought to be in a coma for years or decades came out of it, long enough to express that no, they have not been comatose, they were fully aware of it all.

Lack Of Support

Back to the issue of autonomy. Is it any wonder some people with disabilities wish to die, when they have no support, and aren't able to grab their autonomy? I can think of many people I have worked with that were suicidal. Guys in their 20's, forced to live in nursing homes because they could not get funding for personal assistance. A woman that had been stuck in bed for 3 years, because her insurance company wouldn't pay for a power wheelchair. A quadriplegic husband who felt he was a burden on his wife who had to care for him, losing her job in the process, because there was no funding for personal assistance. A mother who wished to give her children away for adoption, because she was unable to provide a roof for her kids - there was simply no wheelchair accessible housing available to her. These situations are, unfortunately, routine. And they explain well the despair of many individuals with disabilities.

The funny thing is that when someone without a disability becomes suicidal, they are advised to seek psychiatric help. They are counselled that things can get better, that suicide is not a viable option (pun intended). Yet, if someone with a disability voices the desire to die, everyone seems to understand, to find that perfectly natural. Look at Elizabeth Bouvia's story. Shocking.

Jack Kevorkian

Comes in someone like Jack Kevorkian, who offers these people with disabilities an easy and "painless" way to die. They take it. They die. They never had a chance to get a power wheelchair, find housing, keep their kids, etc. The offer of physician assisted suicide is entirely too tempting. I already wrote about Kevorkian's nearly 150 murders. I won't repeat myself here, other than noting that the majority of Kevorkian's victims had disabilities no more "severe" than my own. He's just one proponent of killing people with disabilities.

Peter Singer

Then another proponent is Peter Singer, chair of the Bio-Ethics at Princeton University, renowned animal rights activist. Singer suggests it should be fine to kill disabled infants up to the age of 21 days, because they are "non-persons". "Singer claims that in order to be "persons" and to deserve moral consideration, beings must be self-aware, and capable of perceiving themselves as individuals through time." [2] Right. So, let's kill "non-persons", shall we? This guy is respected although not respectable as far as I am concerned. Chair of Bio-Ethics at Princeton University. Is Singer the kind of guy you would go to to establish strong controls when writing legislation and policies around legalising physician assisted suicide?

52% Of Americans Would Rather Be Dead Than Disabled

But what about Joe Q Public? There was a survey in 2008 that showed that 52% of the American public that said they would rather be dead than disabled. Wow! More than half the people said better death than disability... I'm not too surprised, because people have told me, to my face, that they'd kill themselves rather than have to use a wheelchair like me. What are they saying, really? They are telling me that my life is not worth living. Well, guess what, I DISAGREE!!! But that's not really different from the doctors we mentioned earlier, is it?

Eugenics, Etc.

Let's not forget that these attitudes towards disabilities are not new. Hitler's Germany killed half a million people with disabilities before they went on to the mass murder of the Jewish people. I'm not using "the Nazi argument" because I have nothing else to say, nor because my argument isn't strong. I am merely illustrating that "better dead than disabled" is not new by raising a little known part of the Holocaust's history. The thing is though that Hitler's ideas were strongly inspired by the Eugenics movement. Which was very active in the United States in the late 1800's and early 1900's... Things are coming "full circle" I guess.

There are now a couple states in the United States that legalised physician assisted suicide. And a few countries in the world, such as the Netherlands, and Switzerland. I would like to see the numbers, the statistics of who availed themselves of this "service". I wonder how many of our elders thought they were becoming a burden (financial and emotional) on their families and opted to die before their time. I wonder how many people with disabilities no more severe than my own were shepherded towards the "final solution"? I really would like to see hard numbers from these places. For some reason, however, these numbers aren't really made available to the greater public. Accuse me of being a conspiracy theorist if you wish, but I wouldn't be surprised that the numbers aren't published because they would show the programmes are NOT used just by people who have cancer and are about to die anyway.

Experiencing Intense Chronic Pain

I'm not a stranger to intense chronic pain. The kind of pain that keeps you awake at night, that is so invasive that you're unable to even think. A pain so pervasive that even laying down without moving is painful. The slightest shake of the head drives knives in your nerves. A mere sheet is excruciatingly heavy. The bed under you might as well be a nail bed. There have been many times where I thought I've wanted to die. But I didn't really want that. I was just expressing my frustration at being in an utterly uncomfortable situation, with no foreseeable resolution.

The deck is stacked against people with disabilities in this "game". Only the game isn't such a fun one, and the stakes are literally a case of life or death.

If You Want To Die, Do It Yourself

So, Sir Pratchett has Alzheimer's and wants to die. I don't begrudge him that. I empathise with his fear and pain, and loss of abilities. But if he's so keen on death, why doesn't he drive himself off a bridge? Claude Jutra, was a well known movie director in Québec who was diagnosed with Alzheimer's 20 or 25 years ago. He announced his diagnosis, and then he disappeared (more info in French). His right. His fully informed right. But Jutra did not open the door to abuse and open season on people with disabilities.

In conclusion

All that to say that I oppose the legalisation of physician assisted suicide because:

- It is illegal now, yet it is happening
- There can be no strong controls
- Medical & societal bias against disabilities
- Provision of appropriate supports instead of killing
- There **is** quality of life with disabilities.

[1] <http://www.notdeadyet.org/docs/factsheets.html>

[2] <http://www.notdeadyet.org/docs/annotatedsinger.html>

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