

# Stop trying to kill us off

## The legalisation of premature death as a treatment option is a threat to disabled people

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Assisted dying is not a simple question of increasing choice for those of us who live our lives close to death. It raises deep concerns about how we are viewed by society and by ourselves. I have a severe form of spinal muscular atrophy, and require 24-hour assistance. Many people who do not know me believe I would be "better off dead". Even more argue: "I couldn't live like that." And some suggest that advances in genetic screening should be used to enable parents to choose whether to have a child with disabilities.

Assisted Dying for the Terminally Ill, Lord Joffe's private member's bill, which will be debated in the House of Lords this Friday, feeds into that lack of knowledge (some might call it ignorance, others prejudice) by endorsing such views and legalising the killing of terminally ill and disabled people. The bill has the backing of the Voluntary Euthanasia Society (recently renamed Dignity in Dying) and, according to their polls, the support of the British public.

Yet it has failed to get the endorsement of a single organisation of disabled people. Three major national charities have condemned it, and leading campaigners have united under the banner of Not Dead Yet UK to make the voice of disabled people heard. The very people the bill is intended to help, the terminally ill and disabled, are frightened by what it seeks to achieve.

Proponents of the bill claim that such criticisms are nonsense: the bill is only intended to help that small minority who, in a similar situation to me, do not think as I do but want to die. While conceding my right to choose life, Lord Joffe deliberately ignores the factors that contribute to my choice. I benefit from excellent medical care. I live in an adapted bungalow, and my local authority provides proper care support that enables me to choose my own personal assistants. I am not dependent on family and loved ones. I love my good life. Lord Joffe, it appears, does not. In 1999, as a member of the royal commission on long-term care for the elderly, he issued a minority report with one other member, saying that social care support should not be free at the point of delivery.

When I think about this, I shudder. To get an image of what it might be like, one has only to think of Diane Pretty. Her life was very different from mine and I would have liked to know the reasons for that. Did she choose to live confined in a downstairs room rather than have adaptations to her home or be rehoused? Did she want her husband to be her

full-time carer rather than accept more support from social services? Why was she not fully confident about how her medical team would take care of her as her illness progressed?

This is the third time that Lord Joffe has tried to get doctors to turn their backs on the Hippocratic oath that requires them to "do no harm". Following each rejection, he has returned with a more restrictive bill. This time, we are told, the bill contains two important safeguards. First, it will apply only to the "terminally ill" - the "disabled" are excluded, so have nothing to fear. Second, the doctor will only be permitted to prescribe the lethal dose. The patient must self-administer, so protecting anyone who requests assistance to die but then has a change of heart.

A moment's thought will show that these are not safeguards but devices to silence objectors. The more restrictive the bill, the easier it is to argue for its scope to be expanded once it has passed into law. None of us will be safe. Consider two patients lying side by side in hospital: both ask their doctor to prescribe lethal medication. Although their symptoms and prognosis are similar, one has a terminal illness whereas the other is classed as disabled. One gets the drugs; the other does not. Or will the second patient be reclassified? Consider the two patients again: one has the strength to swallow the poison; the other does not, so it remains by the bed. The message: "die now - before it's too late."

Legalising premature death as a treatment option will place pressures on people near the end of their lives. It will be the cheapest, quickest and simplest option - all more attractive to health and social care services than developing and providing expensive, and potentially long-term, services. The relationship between care givers and receivers will be irrevocably damaged.

Fortunately, disabled and terminally ill people aren't going to let that happen without a fight. Lord Ashley, the life-long campaigner for disabled people, is introducing a bill on the right to independent living later this year to guarantee the services that people like me need to participate fully in society. If Lord Joffe really wants to help, he should start listening and stop trying to kill us off.

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