

Assisted Dying; A question of choice?

Jane Campbell

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My presentation is not centred on a moral or ethical position on the right to live or die. I believe there are compelling arguments for and against this so called right for physician assisted dying. However, what I wish to discuss here, is that it is impossible to introduce a regulatory framework which would ensure that disabled peoples' lives are not put at risk in today's society. Our current socio-economic climate discriminates against people with severe disabilities and illnesses. I will argue that our lives are seen as inferior to those of non-disabled people. Therefore, legalising euthanasia or even assisted suicide would place disabled people in potential danger. I will use the recent Assisted Dying Private Members Bill as a vehicle to explore my concerns.

Last spring, on the 14th May the House of Lords debated Assisted Dying for the Terminally Ill, a Private Member's Bill presented by Lord Joffe. 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 the Bill has failed to get the endorsement of a single organisation of disabled people. Three major national disability charities have condemned it along with growing numbers of individual disabled people who have united under the banner, Not Dead Yet UK, to make their concerns heard. NDYUK members gathered outside the House of Lords during the debate and were overjoyed when the private members Bill was defeated by 148 votes to 100.

So why are the very people the Bill was intended to help – terminally ill and disabled people – so frightened by what it sought to achieve (namely, freedom of choice and from unbearable pain)? The answer is that this is not a simple matter of increased choice for those of us who live our lives close to death. The fact is, the Bill raises deep concerns about how disabled people are viewed by society and by ourselves. Many people who do not know me believe I – Jane – “would be better off dead”. Even more argue that they “couldn't live as I do”. This Bill fed

into a lack of knowledge (some might call it ignorance, others prejudice) by endorsing these and similar views and by proposing it should be legal in certain circumstances to end the of lives of terminally ill and severely disabled people.

Proponents of the Bill claimed this was nonsense. The Bill was intended to help that small minority who (in a situation similar to mine) do not think as I do, but wish instead to die. They said the Bill was not about disabled people but about those who are terminally ill, during the last few months of their lives [ignoring, by the way, the evidence of professional medical organisations who have reported that prognosis of date of death is extremely difficult].

Supporters of the Bill cite people having conditions such as Multiple Sclerosis and Motor Neuron Disease as the potential beneficiaries of this law. This confused me, as people with these conditions ARE disabled people.

Anyone qualifying for an assisted death under Lord Joffe's Bill would meet the definition of disability set out in the Disability Discrimination Act. What Dying in Dignity campaigners were doing was feeding into the medical model of disability which only judges people on their 'condition' or 'impairment'. We may feel that it is a compassionate act to help someone end a life that is

intolerable to them. The danger is the assumption that disability, in this case the physical condition brought about by Multiple Sclerosis, is sufficient to explain the intolerable nature of that life. I cannot emphasize this distinction strongly enough.

On more than one occasion, Lord Joffe has said, "I only want to help". However, his eagerness to help people with such conditions into the next world is not matched by a similar commitment to help us in this world. Whilst conceding my right to choose life, he deliberately ignores the factors that contribute to my choice and that of people like me who have so called terminal conditions.

I benefit from excellent medical care. I live in an adapted bungalow, my local authority provides proper care support in the form of a Direct Payment package that enables me to select and employ personal assistants. I have a powered wheelchair and other assistive technology, some of which I used to write this speech. Without this social and health care support, I too might feel suicidal.

Lord Joffe does not seem to connect the importance of public service support with personal well-being. In 1999 as a member of the Royal Commission on Long Term Care

for the Elderly, he and a colleague issued a minority report, saying that social care support should not be free at the point of delivery. In his view we should look to relatives and friends for our care needs.

Joffe and his supporters fail to recognise that every day in Britain a disabled person is made fully aware that his or her life is contingent on the goodwill of others. There is no right to Independent living or palliative care. As the Bill said - *'inform (the patient????) of the benefits of the various forms of palliative care and social care'*, but there is no guarantee in law that palliative care will be available.

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. I never met Diane but I wish we could have spent some time together. Her life was very different to mine and I would have liked to know the reasons for that. Did she choose to live confined in a downstairs room rather than adapt her home or be re-housed? 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 of how her medical team would take care of her as her illness progressed?

Research evidence from the UK and abroad from palliative care specialists shows that most people who seek assisted suicide give "not wanting to be a burden" as their principal reason for seeking death.

Epithets such as "tragic", "burdensome" and even "desperate" are frequently used to describe disabled people's lives, and unless you are extraordinarily strong it's all too easy for disabled people to succumb to this negativity.

Another reason people give for wanting to die is pain. If you are asked: *"Would you prefer to be assisted to die rather than be in "unbearable" pain?"* The answer seems straightforward. But is it?

Let me tell you Alison's story,

"I am 47 and was born with severe spina bifida. I am completely dependent on my wheelchair for mobility. I am doubly incontinent and I have the lung condition emphysema which often makes breathing very difficult. I also have osteoporosis which has caused my spine to collapse, trapping nerves. This causes extreme pain which is not always controlled, even with morphine. When the pain is at its worst I cannot move or speak. This can go on

for hours, and there is no prospect of relief. Some years ago a combination of the above led me to feel that I couldn't go on living. For ten years I wanted to die and I made several serious attempts to kill myself. I hoarded painkillers and swallowed huge overdoses, washing them down with whatever alcohol I could lay my hands on. I wanted death, and I knew exactly what I was doing.

Fortunately for me, I have friends who were brave enough to intervene, who called 999 and had me rushed to hospital. I was treated against my will more than once.

If euthanasia had been legal, I would certainly have requested it and I wouldn't be here now. In fact, under the rules that now apply in Holland; I would have qualified for euthanasia back then. Two things helped me realize that, in spite of my many disabilities, life can be sweet.

The first is my friends who refused to accept my view that my life had no value. They helped me re-establish a sense of my own infinite human value, a value which isn't diminished by being severely disabled and having to depend on others.

The second is that I went to India to visit two children I had been sponsoring through a project to help those with disabilities –they were to change my life completely.”

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Alison went onto to form a charity that provides assistance to disabled children in India.

Alison is far from unique. RADAR has recently published a booklet, “Assisted Dying – the facts” which includes a collection of personal stories similar to Alison’s.

Some will argue that enough safeguards can be included in the proposed legislation to calm the fears of myself and the other disabled people I have been describing. The latest draft of the Bill claimed only to help people in the last stages of illness. The reality is that there can be no watertight safeguards to determine whether a person is indeed terminally ill and in the last months of life, whether they are "suffering unbearably", nor even whether the cause of that suffering is the illness itself, or unmet physical, mental or social needs.

Who actually "qualifies" for the right to be assisted to die under the proposed legislation is therefore highly contestable. Not only would doctors be presented with impossible dilemmas about when to treat and when to

assist to die but, if physician assisted suicide were once to be legally sanctioned then, *limiting* access to such assistance to die could be said to be discriminatory.

For this reason there would inevitably be calls to extend the legislation, and over time to include more and more people in the name of equality and human rights (as has proved to be the case in Holland). The slippery slope that so many reject as anecdote, will reassert itself as it has done so in the past.

Let us just consider for a moment, one news item that has been circulating in recent weeks. The press got hold of The Royal College of Obstetricians and Gynaecologists' (RCOG) submission to the Nuffield Council on Bioethics, regarding the ethics of prolonging life in foetuses and the new born. Although stating that the welfare of all mothers and babies requiring care because of premature birth delivery is of paramount concern, the RCOG has called for consideration of “widening the management options available”, specifically, non-resuscitation, withdrawal of treatment, the best-interests test and active euthanasia. Personally I was appalled that RCOG is only interested in “options” negative to the life chances of the disabled child. I became even more worried when document went on to say that the RCOG, “...does not have a view that we

would like euthanasia to be discussed but do feel it has to be covered and debated for completion and consistency's sake..." I feel that the reason why the RCOG needs to use such convoluted language is because of their evident awareness that its views will be widely seen as unpalatable.

For the RCOG to consider changing that right in relation to disabled children on the grounds of cost and a better deal for parents is a contradiction to the very nature of medical practice. Would this not become an exercise in social control which can only be described as eugenic?

Members of NDY UK include many severely disabled people, some of whom, including myself would have been denied life had it not been for the efforts of the medical professionals present at their birth. It distresses me to think that such care might be withheld from similar infants in the future because proposals put forward by RCOG slowly become more acceptable. Disabled people have benefited from advancements in medical science. Now it seems the RCOG wants to temper these advances by introducing a set of value judgements that reflect fear and prejudice about disability.

Only last weekend, following on from the RCOG's submission, the press reported that the Church of England also supports the active euthanasia of severely disabled babies. The Church's reason is compassion. Medical treatment can be invasive and painful. Better let a baby die than give an injection that will make it cry. Like the RCOG, the Church is also concerned with cost issues.

If the RCOG consultation submission is not advancing the slippery slope I don't know what is. For me, this and Lord Joffe's Bill, are the very epitome of the slippery slope. Following each previous rejection, Lord Joffe has returned with a more restrictive Bill. This time, we were told, the Bill contained two important safeguards. Firstly it will apply only to the "terminally ill" - the "disabled" are excluded, so have nothing to fear, surely a disingenuous proposition. Secondly, the doctor would only be permitted to prescribe, not administer, the lethal dose. The patient must self-administer, so protecting anyone requesting assistance to die but then having a change of heart.

A moment's thought will quickly show that these are not safeguards but mere devices to silence objectors. The more restrictive the Bill, the easier it will be for supporters to argue for its scope to be expanded once it has passed into law. Many disabled people will simply not be safe. Consider two patients lying side by side in hospital, both ask their doctors to prescribe lethal medication. Although their symptoms and prognosis are similar one has a terminal illness whereas the other is classed as disabled. The terminally ill patient gets the drugs the disabled patient 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 at his bedside. The message: “die now – before it's too late”. I am stating the worst-case scenario, but this rationale is entirely sanctioned in the Assisted Dying Bill!

Legalising premature death as a treatment option will place the seed of doubt about one's right to demand help to live with dignity. I believe it may place pressures on people who think they are close to the end of their lives to consider death as preferable to fighting for support to live with dignity. It will be the cheapest, quickest and simplest option. In addition, think of older people who are anxious not to cause their families any distress! It may become

more attractive to health and social care services than developing and providing expensive and, potentially long-term, services.

Having looked at the evidence from Holland and listened to debates in the House of Lords two weeks ago, I am persuaded of the slippery slope argument. By way of example, let me quote Lord McColl who recently made the case as convincingly as I've heard it. He said,

“When a Dutch doctor was asked what his first case of euthanasia was like he said, it was dreadful. We agonised all day. But the second case was much easier and the third case was a piece of cake. Many elderly people in Holland are so fearful of euthanasia that they carry cards around with them saying that they do not want it.”

Or consider the physician in the Netherlands who reported assisting a person to die who had made no request, based on the fact that he believed the patient's personal beliefs would impinge of the likelihood that she would request assistance despite her condition. She was a nun! Imagine the potential for abuse of legislation based on misconceptions of where to draw the line between the

stated opinion of an individual and assumptions made about quality of life.

If assisted dying becomes law I believe the relationship between care givers and receivers will be irrevocably damaged.

I believe the background noise to this debate is reinforcing negative perceptions of disability. It feeds into desires for a body beautiful and a perfect life untroubled by illness. It promotes premature death as a choice option, especially for people with severe disability or terminal conditions. The “choice” agenda is false because it actually means less choice. To make a real choice we need to live in a society that values us equally, where we can live with dignity and have access to proper pain relief. Only when that happens would I be prepared to have the debate about the choice to end our lives. Personally I don't think people will wish to die in such a climate.

Fortunately, disabled and terminally ill people are entering this debate, making people think about the consequences of such a lethal law. Hence, for example, the creation of Not Dead Yet UK.

Thankfully, there is an antidote to Lord Joffe and his solution to personal distress. This year Lord Ashley, the life-long campaigner for disabled people, is introducing an Independent Living Bill to guarantee the services that terminally ill and disabled people need to live with dignity. This will be the Bill of hope whereas Joffe's was the Bill of fear.