

Philip Friend OBE

By way of introduction, I contracted polio when I was three. I've therefore been disabled for most of my life. So, for me, disability has always played a major role in my life. When I caught polio I was placed in an iron lung because I was completely paralyzed and couldn't breathe. And doctors and other medical professionals did everything they could to ensure that I survived that experience. What I want to remind you the listeners is that the medical profession plays an absolutely crucial and vital role in the lives of all of us, but particularly those of us who have disabilities or long-term health conditions, we are frequent users of their services. And there's no doubt in my mind that without the care and attention I received, I wouldn't be talking to you now.

I am writing on behalf of the organisation named 'Not Dead Yet' which represents many people with disabilities globally and in the U.K. I have become aware of the proposition due to be debated in the States of Jersey Assembly on the 21<sup>st</sup> May 2024 and there is currently an opportunity for individuals and groups representing disabled people. This consultation I understand will be just 2 sessions coordinated by Enable Jersey and Acorn. I am writing this to express my grave concern that this would not be a sufficient assessment of the wider views of disabled persons. In 2018 the Guernsey Alliance which represents many of the groups supporting disabled persons, campaigned against Assisted Dying. Disabled people in Jersey are not as well represented in comparison. What happens in Jersey will also influence the debate in the U.K. mainland jurisdictions.

Various Bills in the U.K. have come and gone to try and change the law on assisted suicide. The scary prospect is the fact that doctors are now going to be asked to consider ending life rather than saving it. That I think completely undermines the relationship that exists between the patient and the doctor. We think that the doctors are the people that protect us and help us to manage thoughts that life is not worth living. A quote that I'd like to use from Robert Twycross, who is a Palliative Care doctor. He says, "Palliative care is based on the belief that life has meaning and purpose, up to the moment of death. Whereas assisted dying is essentially nihilistically expecting health professionals to deliver both palliative care and assisted dying, in other words, to face in two directions simultaneously, is too big an ask".

### **Coercion, being a burden and the perceptions of disabled people or disabilities:**

Historically, disabled people or those with disabilities have been seen to be about suffering, pity, hopelessness, and tragedy. These words are used to describe both the disability and disabled people. But there is no doubt in my mind that disabled people are still viewed pitifully. And while that is the case, it's very easy to take the view, that it would be easier for this individual to end their lives. To "put them out of their misery" After all they can't be successful can't hope for futures, they can't aspire to do things.

Turning to safeguards contained in the proposed that suggest that there are adequate protections for disabled people. Some of these 'safeguards' are based on the notion of consents and involvement of families in the process. I'm reminded that some families are not nice. Some families do not treat their family members well, particularly their disabled family members.

A former Court of Protection Judge, Denzil Lush, has estimated that one in eight Lasting Powers of Attorney may involve financial abuse. And according to a 2015 report by Age UK, 50% of financial abuse of elderly people in the UK is perpetrated by adult children. So, when we think about the idea of covert coercion, etc, it's worth reminding ourselves that it's very difficult to understand the dynamics of families and therefore extremely difficult to protect the vulnerable or those at most risk from their relatives. The safeguards don't inspire much confidence in my view.

The recent experiences of COVID have taught us that resources are scarce that life or death decisions are made on whether resources are available. I think that until the state, and I use that term very generally sees disability as a positive issue, rather than a negative one, then continuing judgments will be made, which do not necessarily work in the best interest of disabled people. We will continue to feel that we are a burden to our families and on wider society.

As I move towards the conclusion, I believe that the safeguards that are currently in place are not safe at all. There is evidence that in every jurisdiction where assisted suicide currently exists, they have been expanded to cover more and more people. And there have been huge percentage increases in the numbers of people applying for assisted suicide.

It is our concern, that you should not focus on personal choice or personal morality but focus on public safety. This must be the primary consideration, in all legislation.

What we want you to do is to help disabled people to thrive, not to die. We are calling on the States of Jersey to reject this proposition and overturn the 'in principle' Assisted Dying law as there are no sufficient safeguards to protect those with disabilities.

Thank you very much.

Philip Friend OBE

On behalf of Not Dead Yet UK

<https://notdeadyetuk.org>