St George's House, Windsor

“Assisted Dying: Be careful what you wish for!”

I am very pleased to be here today to contribute to this important St. George’s House consultation. I want to talk to you from my personal perspective as a severely disabled person and as Convenor of Not Dead Yet UK. For those of you who may not know already, Not Dead Yet UK is network of disabled and terminally ill people opposed to any change in the law on assisted suicide. I want to concentrate on three issues that are often raised by members of Not Dead Yet UK: choice, safety and equal value.

Calls for Assisted Dying to be legalised have grown from a background murmur into a roar since my colleague and friend here, Lord Joffe, tabled his Assisted Dying for the Terminally Ill Bill in 2003. His bill led to a House of Lords Committee on the issue and a revised Bill was put before the House in 2005. Despite the Bill being defeated, several Members of both houses have stated their intention to bring another, revised Bill back in this Parliament. In the past few years there has been considerable press interest in assisted suicide. We have seen the high profile Court cases of both Diane Pretty and Diane Purdy. There have been numerous accounts of Britons going to Dignitas. Most recently a high profile celebrity, Terry Pratchett has talked up the cause.

These developments are beginning to have a serious effect on the lives of disabled people. Disabled people, many of whom have progressive or terminal conditions, are becoming increasingly worried about a reform that is supposed to help them, and when their situation becomes unbearable. The consensus would seem to be that there is nothing more humane than assisting another person to die, especially if that person is in pain, distress or expected to die within months, rather than years.

Proponents of legalising this approach have, with each successive rejection, re-drafted their plans to narrow the eligibility criteria. However, most would agree that, should I wish to end my life, I should be assisted to do so, since I would find it impossible without such help. I couldn’t leap from a tall building, unless someone put a lift in first. I couldn’t swim out to sea, unless someone put me on a lilo and towed me out into deep water. I couldn’t cut my wrists, unless someone else held the knife. I couldn’t swallow a bottle of aspirin unless someone opened the bottle for me and patiently lifted the glass to my lips. Surely then, I should welcome the option to end my life at a time of my choosing, as others who choose suicide do? After all, suicide is not illegal.

The proponents of legalising Assisted Dying, very few of whom are terminally ill or disabled, certainly want to give me the option of “choice”. It is not unusual for me to be told, “I couldn’t live like you ” or “You’re so brave, I know if I were in your position I wouldn't cope ”. I wonder how you would you feel if others thought you’d be better off dead? OK, that might be a

bit strong. How would you feel if people assume you want to die because, in their eyes, your life must be unbearable? That's their mistake you might say. But if they are the doctors and nurses treating you when you're seriously ill and fighting for your life, it's a mistake you might not live for them to regret. What if they've already assisted 1, 2, 5, or 20 people like you to die, how hard are they going to fight to keep you alive?

Research in Holland has shown that what began as a very unusual end-of-life choice for those in the last few weeks of a terminal illness, soon became a routine option for disabled people without a terminal diagnosis. Perhaps the most compelling evidence given to the House of Lords came from Dr Bert Keizer, who worked as a geriatrician in Amsterdam for a quarter of a century and carried out many "physician-assisted suicides"– the basis of his book "Dancing with Mr D". Dr Keizer said, *"It is useless to worry about the slippery slope. Once a society has decided that euthanasia is allowed in certain cases, one is on it. Thus in Holland we have given up the condition that a patient must be in a terminal situation. Next, mental suffering was allowed [as a reason]. Then one's future dementia was suggested as a reason for a request for death . . . I believe, on the grounds of the more than 1,000 deathbeds I attended, that euthanasia is a blessing in certain exceptional situations, yet I would rather die in a country where euthanasia is forbidden but where doctors do know how to look after patients in a humane manner."*

It is all too easy to make assumptions about lives very different from our own; All too easy to believe that another life has less quality than our own because it is different; All too easy, to believe that we wouldn't be able to cope if our circumstances were to change dramatically; All too easy to believe that our family and friends would not accept illness and disability; All too easy to assume difference means less and change can only be negative. The reality is dramatically different. Working alongside disabled people and listening to their stories, I understand why they fear the slippery slope.

Daniel James went to Dignitas, 18 months after a rugby accident broke his neck. Press reports almost unanimously conveyed it as a tragic but completely understandable act. His wish to die was considered acceptable because he had become seriously disabled. The same desire to die in a non-disabled person of any age, whatever their problem, would be considered to be unreasonable and potentially a sign of mental illness. To many people Daniel James's desire to end his life, whilst wholly undesirable and deeply regrettable, was understandable (i.e. they empathised with it) for no other reason than that he had lost physical function. This "understanding" of a disabled or terminally ill person's wish to die is deeply demeaning to most terminally ill and disabled people. It sends out entirely the wrong message to those newly disabled or diagnosed with a terminal illness. Indeed, society's "understanding" of Daniel James's decision may have contributed directly to it. We are not immune to the drip-drip negativity of what it is to be disabled. It is prejudice and it is disability discrimination.

When we talked about this in Not Dead Yet UK, one of our members, Dr Ian Basnett, now a talented Director of Public Health, took us back to when he was a Junior Doctor working in a hospital A&E department. He encountered young men admitted with broken necks as the result of motorbike and workplace accidents. He remembers thinking he would rather die than live with a broken back or neck. He then broke his neck in a rugby accident. He felt for a long time after his accident (at least three years) that life was not worth living. He is in no doubt that he would have done the same as Daniel James during those years if it had been possible. He says that, if Daniel James had not become tetraplegic but wished to die as the result of some other life changing event - say, the death of a child, psychiatrists, doctors and lawyers would say he had post traumatic stress disorder and needed support to come to terms with that situation. Suicide would never have been considered a rational response. To see suicide as the right solution is to abandon hope. Ian and members of NDY UK believe there will always be individuals who ask for society to be complicit in their premature deaths, especially after experiencing life changing illness or disability. Society must treat them as everyone else is treated, as people with rights and responsibilities, able to make a contribution to our collective well being. Entitled to help to live, not help to die.

Some of you may be thinking, *"Yes, that's all very well. We know YOU don't want to die. We know most disabled people don't want to die. That's not the issue. Assisted dying is all about helping the few, perhaps the very few, who genuinely want to die. Surely we can change the law to help them?"* This is the stated aim of some in the House of Lords. It feels like they are engaging in a "Sudoku" puzzle, that they are determined to crack. Drafting legislation that empowers the few whilst protecting the many is, needless to say, a challenge!

Perhaps it's worth reflecting on that other area of assisted dying that the state took a settled view on several years ago – capital punishment! Received wisdom is that if asked in a referendum, the British public would call for the re-introduction of capital punishment. Yet successive governments for the last 40 years have kept clear of the issue. The view is that, even with tightly drawn laws mistakes are possible. A wrongly convicted prisoner can gain freedom but the executed cannot be resurrected. There's also the view that the state taking the lives of its citizens is wrong, not on religious grounds but because it is an affront to civilisation. We look disapprovingly on countries that continue to practise capital punishment. We suspect their motives and accuse them of "human rights abuses".

The facts that many murderers admit their guilt, that many cases are "open and shut" without any room for doubt does not sway us in the view that capital punishment is wrong. Even if a murderer were to plead to be executed, to vow to kill again until himself killed, the state would not sanction his execution. We would not answer his plea to be killed. Yet, despite this, to take the life of a severely ill or disabled person at his or her own request is now being promoted as a noble act worthy of the state's blessing.

Disabled people know about choice and control. We know that assisted suicide is not about free choice and self-determination. The evidence from the state of Oregon shows that it undermines patient control. We cannot understand

why Oregon is continuously cited as safe and working well? The number of assisted suicides there has risen fourfold in the 12 years since the law was enacted. Research indicates that as many as one in six of those who have killed themselves with the help of lethal drugs from their doctors were suffering from depression. Moreover, there is no way of knowing under the Oregon law whether, once lethal drugs have been issued, they are taken as intended – i.e. by the person concerned without anyone else's involvement.

NDYUK was formed because we realised the voice of the majority of disabled and terminally ill people was not being heard in the debate on assisted suicide. We believe we can help by showing how important it is to debate this issue in the context of society's cultural response to illness and disability. No organisation of or for disabled or terminally ill people has campaigned for a change in the law on assisted suicide. You may have been wondering why the people a change in the law is intended to help, are so set against it? I hope my paper has helped you recognise our fears to be genuine. A change in the law would not only be bad for disabled and terminally ill people, it would be back for society.