Select Committee on the Assisted Dying for the Terminally Ill Bill [HL]
evidence to the Committee submitted by Dr Jane Campbell MBE

Assisted Dying and Human Value

by

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Introduction: Supported-Living Values *versus* the Dying Process

§ 1

Over the last several years the campaign for euthanasia has gained momentum. Individuals talk of wanting not to die in pain, with indignity and the loss of control of bodily functions. They talk of being a burden on friends and family. Severe incapacity or terminal illness has always been a taboo subject in our society. The general population deeply fear losing their mental or physical faculties and feel the answer to that anxiety may well lie in euthanasia legislation. It is my view that before we consider regulating the dying process we need to deal with society's deeply held prejudice about the quality of life of people with a so-called terminal illness. For it is my belief, that until we introduce supported living values into the psyche of our society, we can never have a balanced debate on euthanasia legislation. For this reason the majority of disabled people in the U.K disabled people's movement oppose this Bill.

§2

In 1999, a global summit of disabled people met in Washington DC, to discuss the situation and concerns of people who require human support to live.[1] The conference concluded with a declaration of principles of interdependent living.[2] The first of these principles states:

"*... that all human life has value and that every human being should have meaningful options to live with dignity and respect.”*

§3

If we accept that all human life has value, it follows that we should strive to value the individual human life. Regrettably, in current society, some lives are deemed more valuable than others. Disabled people who live with a terminal illness tend not to be seen as leading meaningful lives as I will demonstrate. Drawing upon my own experience and the evidence I have gathered from working and campaigning within the disabled people's movement over the past 25 years, I will argue that severe I incapacity is typically perceived to be an inferior state of being. In such circumstances, legalising euthanasia or as Lord Joffe's Bill calls it “assisted dying " risks the lives of people with no wish to die. My evidence is not centred on a moral or ethical position on the right to live or die. What I wish to discuss here is impossibility in the present climate of opinion of ensuring that terminally ill lives will not be put at risk.

My Personal Concerns about a Growing Euthanasia Culture

§4

When I was born, my mother was advised to take me home and enjoy me as I would die within a year. As can happen with the prognosis of terminal conditions the doctors got it wrong. Although I was frequently unwell, mostly with life-threatening chest infections, I was treated with life-saving antibiotics and ventilation and thrived in this positive medical environment. Happily, some 40 years later, I remain very much alive.

§5

But I have noticed a change over the last two or three years, especially ,in the aftermath of the high-profile Diane Pretty case, which has influenced

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[1] “Global Perspectives on Independent Living for the Next Millennium”, an international summit conference on independent living, Washington, DC, 21-25 September 1999

[2] The full list of principles, known as “The Washington Declaration” can be accessed on the Independent Living Research Utilization website: www.ilru.org/summit/index.htm

public opinion, including that of some medical professionals, to generalise Pretty's situation to all patients with diagnosed terminal conditions. Devastating is not too strong a word to describe an experience I had in January 2003, when I was admitted to hospital with severe pneumonia in both lungs and required emergency treatment.

§6

The consultant who was treating me commented: "You are very ill. If you go into respiratory failure I am assuming that you do not want to 'be resuscitated with a ventilator." I was a taken aback by this and said, 'Well, why?' He replied that the chances of weaning me off the ventilator would be very remote - "And you wouldn't want to live on a ventilator ." When I said that meant I would die and of course I want to be ventilated, he looked (I thought) puzzled but appeared to let the matter drop.

§7

The next day I was in intensive care when another, more senior, consultant repeated the same message: "If you go into respiratory failure - and this looks likely - then I am sure you won't want to be anywhere near a ventilator." Again I protested but by now I was getting very scared. My husband tore home, grabbed a photograph of me in my doctoral graduation robes, and returned to the hospital shouting to the doctors: "This is my wife, not what you think she is. She has everything to live for. You do everything for her just as you would for anybody in this situation." Such extreme measures helped bring about a change of mind and I have lived to tell the story, albeit I kept myself awake for the next 48 hours, fearful that if I went to sleep I'd never wake up.

Does this experience speak for others? Am I the lone voice?

§8
In the UK, the Disability Rights Commission, Disability Awareness in Action and similar organisations are gathering evidence about assisted dying from disabled people and their families. These works in progress are demonstrating that decisions regarding life-saving treatment are often made in an environment of ignorance and discriminatory attitudes towards and about disabled people. In addition, society's obsession with image and the body beautiful reinforces negative stereotypes that disability is equal to a state worse than death. This personal submission of evidence for the Select Committee is not the place for comprehensive report and analysis on research within the disability community on this issue. However, I would like to quote a small number of individuals from within the disability community who perceive the proposed legislation to be a threat to their own safety and well-being, and/or think such legislation will exacerbate a culture of negativity around severe disability or illness.

§9
Michelline Mason Chief Executive of the Alliance for Inclusive Education, says that

A message over the years clearly and firmly slipped into my unconscious, saying that people would prefer it if I died. It seems that since then I have spent nearly all my life desperately trying to prove that I should be alive, that I was not suffering (even when I was) [and] that I was not worthless, but indeed exceptionally worthwhile. [3]

§10
Michelline, diagnosed from birth with severe brittle bone disease, had the wherewithal to resist her social fate, but many severely incapacitated individuals are in danger of succumbing to the negativity that can lead to suicide, and these are among the very people with a diagnosed terminal illness that the Bill is targeting.

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[3] personal communication

Roy Webb, Head of Policy, National Centre for Independent Living (NCIL), writes:

This [Assisted Dying] Bill adds to the negative images of disabled people by focusing on the pain and suffering that we sometimes experience. The Bill will, in my opinion, add to the general public view that if you are ill or disabled and certainly if you have a terminal illness, that your life is somehow inferior to that of other people. In fact, although I have [Multiple Sclerosis) and this is sometimes described as a terminal illness, this has never been any concern to me in my life If [people with terminal illnesses] are getting the support they need and can live the life they choose, perhaps they will not feel the need to bring their lives to an end. [4]

§12

As members of the Select Committee will know, the Member's Bill on Assisted Dying was defeated last year largely on the grounds that it threatened the lives of disabled people. In response to this objection, the Bill has been re-drafted, narrowing its scope to the terminally ill. Roy's testimony highlights the fact that people with Multiple Sclerosis, Motor Neurone Disease, Altzheimer's Disease, Parkinson's Disease etc -in other words, the chief alleged beneficiaries of assisted suicide -do not make such easy distinctions between disability and terminal illness.

§13

In 2000, **Rachel Hurst,** Director of Disability Awareness in Action (DAA), made the following plea on behalf of disabled people to the Bioethics community at their 5th World Congress:

It takes a particular sort of courage to rise above these negative impacts and have a faith in your own worth, or the worth of your disabled family member. It takes courage and a clear understanding that disability arises from the social barriers of attitude and environment to your impairment, not the impairment itself. .Just as we all recognise that society need the difference of women and people of different races and backgrounds, so society needs people with impairments.[5]

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[4] personal communication

[5] R Hurst, “Ethics and Disability, Celebrating Diversity”, Paper to 5th World Congress on Bioethics, Solihull

Fear, Bias and Prejudice Against Terminal Illness

§14

My own experience and that of others demonstrate the strength of negative beliefs about severe impairment prevalent in our society. The perception that disabled people with terminal conditions live flawed and unsustainable lives is one of these negative beliefs. The belief that death is preferable to severe impairment is another. It is difficult enough encountering these attitudes in day-to-day living. In the context of Assisted Dying it is more worrying that such beliefs are sometimes held by medical professionals who, let's face it, are ordinary people like the rest of us, subject to much the same social stereotypes.

§15

In 1999 an eighteen month old child, ('Baby C'), with Spinal Muscular Atrophy (SMA) was denied ventilation to help her through a chest infection. The decision was made on the basis that her "disability was too terrible to live a quality life". In addition she would need "total bodily care for the rest of her life" and this would be a "burden on state resources and family support.[6] The family did not accept this decision and took the hospital to Court. The Judge ruled for the hospital having received advice from a range of doctors, who all categorically stated that no one with this diagnosis could live beyond the age of two, and even if they did, their life would be little short of a living hell. Adults including myself can tell a very different story about living with SMA. The baby died as a result of being denied the health care offered routinely to non- disabled babies with severe chest problems. The view taken by the doctors in this case demonstrates the prevalent attitude in society.

§16

Seventeen years ago **Dr Ian Basnett,** a young doctor with everything to live for, was left quadriplegic following a sporting accident. He admits that before the accident,

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(UK), 2000.

[6] R Daw, "The Impact of the Human Rights Act on Disabled People", Report prepared for DRC & RNID, 2000

...like many people, I had a terribly negative image of disability. When you suddenly become severely disabled you still have that viewpoint. Before I was disabled, I was working as a junior doctor. That brought me into contact with disabled people and I remember admitting a man with quadriplegia. My reaction was, 'how could anyone live like that?[7]

§17

The Disability Rights Commission (UK) is unanimous in its opposition to the passage of this Bill. Members of the Select Committee will also be aware of similar opposition by disabled people in other countries.[8] There is no disabled peoples; collective in the UK that seeks passage of this Bill.

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Some individuals seeking the legalisation of Assisted Dying claim this is a human rights issue. I am not alone in repeatedly drawing attention to the fact that human rights are as much a social issue as they are a matter of personal autonomy and neither can be considered in isolation.

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[7] I Basnett, "Will to live wins over the right to die", Observer (March 2002). Dr Basnett is now Deputy Director for Public Health, London Northeast NHS Regional Health Trust

[8] Marilyn Golden, a policy analyst writing for the Disability Rights Education and Defense Fund (DREDF) in the USA summarises the case against the legalisation of assisted suicide in a succinct article available on the internet "Why Assisted Suicide must Not Be Legalized": http://dredf.org/assistedsuicide.html

§19

The Voluntary Euthanasia Society (VES) has reportedly described people with MS as being incurably ill, and those who wish to assist them to die as performing a supreme act of compassion. This view demonstrates the strength of such a negative medical model. We may feel it is a compassionate act to help someone end a life that is intolerable to them. The danger is the assumption that terminal illness alone, in this case the physical condition brought about by Multiple Sclerosis, is sufficient to explain the intolerable nature of life. This will be dependant upon many other factors, such as the home environment, physical barriers, the level of care and support available and access to other individuals living with the condition.

§20

If I were to be denied my electric wheelchair, my adapted home, my accessible vehicle and my personal care assistants, I might conclude that my life was intolerable. With them I am able to enjoy a high-quality life.

§21

Assisted Dying might be, a viable alternative if good quality palliative and social care becomes available across the country. At present this kind of support is patchy at best. If someone chooses death in the absence of such support, their decision is likely to be influenced by this fact.

§22

While the Assisted Dying Bill aims to address the needs of patients in the last stage of their lives, I am concerned about the underlying message of the Bill that death is the preferable solution for people severely incapacitated or in pain. Much the same message is communicated to older people who fear being a burden to others, and to terminally ill and disabled people with inadequate care packages. These views will be legitimised if the law is changed to concede that they might be better off dead.

§23

I cannot accept the dangers that would attend assisted suicide in the current climate of opinion. Diane Pretty was a British disabled person who went to the European Court to fight for the legal right to be assisted by her husband to die. What alarmed me and confirmed my fears was the public and press response to her situation. Every newspaper supported the 'mercy killing' of those with terminal impairments.

§24

Assisted suicide is not an issue that can be resolved by experts alone. On the basis of press coverage of the Diane Pretty case, the public could be forgiven for believing that everyone with a substantial degree of disability will inevitably be deeply depressed and pre-occupied with thoughts of dying. It is significant that her campaign was never questioned in the media.

§25

The consequences of legalising assisted dying are so dangerous that it cannot be considered until society is committed to assisted and supported living for the terminally ill. We must find ways to make life more comfortable for terminally ill people. We need to question the precise circumstances in which a person decides life is not worth living. To assume that the condition itself is the answer is to take too little account of the social, economic and personal contexts of illness.

§26

Society seemed content to consign Mrs Pretty to the graveyard without looking more closely at the conditions leading to her wish to die. It is difficult to imagine such a simplistic scenario were Stephen Hawking to contemplate assisted suicide. Do we want Hawking to live because of his intelligence? Where do we draw the line?

§27

Despite advances in modem medicine, we are all still fearful of serious illness and to any impairment that may reduce our capacity either physically or mentally. This includes even the aging process. Physical impairment flies in the face of our fixations with the 'body beautiful' and looking and staying healthy. We spend millions on cosmetics and other remedies to perpetuate the myth of youth, while closing our eyes to social pressures that lead many people diagnosed with terminal illness to view death as the preferred option. I will feel safe only when society recognises the benefits of creating inclusive communities which embrace physical and mental diversity. Only then can we realistically consider the protective measures that need to be in place to ensure the viability of assisted dying legislation. When the debate and resources and framework are properly in place so that people can live with terminal illness, then we can consider options for people who persist in their desire to die.

§28

We exacerbate a culture where death is considered an answer before we look at how society can incorporate and support such lives within the mainstream. I have been contacted by many disabled people who are still concerned about the potential consequences of this Bill -concerned that people with terminal illnesses may be put under pressure, overt or covert, to choose death rather than be a burden on relatives or the state. Physical and mental diversity are part of the human condition and most of us will have to face up to terminal illness before we die. We can face up to it or fear it. These are complex issues, and there is no easy consensus. The visibility of disabled people who are contributing to the welfare and productivity of society encourages able-bodied people to be more compassionate and constructively facilitative.

Conclusion: Valuing Life With Terminal Illness

§29

If we agree that all human life is of equal value, then we must put our energy into ensuring that our environment and social systems support the inclusion of terminally ill people’s lives. The campaign for this Bill is dangerous Because it reinforces the current unequal value on life and leaves people like me feeling very unsafe.

§30

The dangers of the current negative social response to terminal illness and disability not only threaten our chances of survival but also mark us out, sometimes fatally. I have already described my own close call with the view that I would be better off dead. It would appear my experience is far from isolated. My consultant neurologist told me that Diane Pretty's campaign made his job more difficult. It planted a seed of doubt in the minds of his patients that their lives will not be worth living once their conditions deteriorate and, inter alia, the most logical response to that would be assisted dying.

§31
Instead of seriously considering all aspects of independent living, this legislation encourages assisted dying before we have fully addressed questions of interdependence and assisted living. Most of society sees people with terminal illnesses and disabilities as people who are flawed and without dignity. But we see ourselves as a vital and proud community, with values of our own that enhance our quality of life, values that could enhance life for all.

§32
In addition to this written evidence, I am willing, and respectfully request permission of the Select Committee, to give an oral submission of evidence at an appropriate date.

Dr Jane Campbell MBE