

NO LESS HUMAN: Voluntary Euthanasia and disability. A personal story



Alison Davis is founder and coordinator of the UK Disability Rights group, NO LESS HUMAN.

Alison has spoken across the globe on disability rights and against voluntary euthanasia and assisted suicide.

This text is taken from a speech she gave on her recent Australian and New Zealand visit.

The terms denoting the killing of human beings, for their own supposed benefit or that of others, have changed out of all recognition since the ancient Greeks coined the term “euthanasia” meaning “a good death.” Progressively this became something of a taboo term, and “assisted suicide” or “assisted dying” have become the preferred term. Usually now the term “dying with dignity” is used to mean deliberate killing, as in the UK where the “Voluntary Euthanasia Society has recently changed its name to “Dignity in Dying,” suggesting that only a procured death is “dignified.”

What hasn't changed is the sort of people regarded as having a right to have their lives ended prematurely. Terminally ill people always seem to qualify for what I'll call, for the sake of clarity, “euthanasia” or “assisted suicide.” Incurably or profoundly disabled people as well as elderly people also often qualify for having their lives deemed “not worth living” whether or not they have asked, or can ask, to be killed.

These people are always viewed by the pro euthanasia lobby as being the beneficiaries of any law to allow euthanasia. However, the slippery slope is at work here, and the

kind of people considered “right to want to die” has widened greatly and swiftly in most places where euthanasia

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has been legalized, even with supposedly “strict safeguards.”

Legalised “Voluntary” euthanasia spreads.

Since Holland became the first country to fully legalize euthanasia on 1st January 2002, after years of it being available there on a pseudo-legal footing, only a few other places have followed suit completely. However, it is being hotly discussed around the world now, and sick and disabled people recognize the threat that is coming ever nearer, even if “assisted dying” is not yet legal in their countries.

The Dutch experience showed that once euthanasia or assisted suicide is allowed, despite any number of so-called “strict safeguards” such as that the killing must be “voluntary,” it is likely to go on to include victims who either did not, or could not, volunteer.

For instance in July 2005 Dutch pediatricians adopted as na-

tional guidelines a protocol from Groningen University Hospital allowing for the so-called “mercy killing” of newborn disabled babies, who clearly can't volunteer! Most of these babies have spina bifida, which is one of the disabilities I have.

Elderly people, especially those with dementia are equally likely to be regarded as “better off dead” in Holland, whether or not they are in a position to actively request euthanasia. People with “mental suffering” and no physical illness have also been put to death in Holland, and euthanasia deaths have even been shown on TV in an attempt to reassure people that it really is “a good death.” This tactic has also been used in the UK, for the same purpose.

“Voluntary” euthanasia is now legal in Belgium, Luxembourg, Switzerland and the US States of Oregon, Washington and Montana, the latter solely by judicial fiat. Bills to legalize assisted suicide are also being debated in several other US states and in countries around the world not least the UK where the pro-death lobby seems to be making phenomenal progress.

Deliberate killing by neglect of vulnerable people leads to calls for assisted suicide.

In 1993 the law in Britain was changed to allow the deliberate killing of Tony Bland, a young

man who was in the inappropriately termed “Persistent Vegetative State” or PVS. This was done by removing his feeding tube, and he died nine days later of kidney failure secondary to starvation and dehydration.

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Since then the Government has admitted that other people in “PVS” or close to it have also been deliberately killed.

Attempts to promote assisted suicide have also gained momentum particularly since 2005, when legislation was passed to facilitate the deaths of profoundly disabled people who did not already qualify for medical killing under the *Bland* ruling.

On 5th April 2005 the Mental Capacity Act was passed in the UK, which allows among other things killing by withholding or withdrawing assisted food and fluids from vulnerable people who are not in “PVS.” It came into force fully in October 2007, after a long and tortuous history beginning in 1989 and went through a cosmetic change of name from the “Mental Incapacity Bill” to the “Mental Capacity Bill”

The change of the name was introduced by the Government

as a result of justified criticisms that the bill would adversely affect incapacitated people. The Government changed the name, but not the content in order to allay these fears and present the bill as something benign.

Suffice it to say the change of name didn't allay our fears, and how can a mere change of name affect the content of a bill. In fact it rather reminded me of a report I read in my local newspaper some years ago, which said “Owing to complaints about the noise from the Fox and Hounds pub in Iver Heath, it has been decided to change its name to the Coach and Horses”!

The latest development of the Mental Capacity Act was revealed earlier this year when the General Medical Council unveiled its new guidelines to doctors. These include the provision that they will be struck off the medical register if they give treatment to patients who have made “advance decisions” or living wills, which state that they want treatment to be stopped, including assisted food and fluids

Because of this law, some argue that people have a “right to die” voluntarily, and that it is only the means that is questioned. After all, if it is acceptable to kill people who cannot volunteer, surely it must be acceptable also to kill those who do? Such people say that it is more humane to have a lethal injection than to starve or dehydrate to death. Thus the prediction made by Helga Kuhse, a long time colleague of the infamous eugenicist philosopher Peter Singer, has shown

itself to be chillingly true. She said:

“If we can get people to accept the removal of all treatment and care – especially the removal of all food and fluids – they will see what a painful way this is to die and then, in the patient's best interests, they will accept the lethal injection.”

Disabled people threatened

Despite the supposed clamour by sick and disabled people around the world for legalized euthanasia, most such people feel very afraid at the prospect, or reality in some places, of

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legal euthanasia. In some countries, notably the UK and USA, profoundly disabled and apparently terminally ill people are already being pushed into death by a combination of sedation and withdrawal or withholding of assisted food and fluids.

This has since developed by way of the so-called “Liverpool Care Pathway.” This was originally developed to help patients in their dying hours and ensure that they were not “over-medicalized.” However, Dr. Adrian Treloar a senior geriatrician, immediately noted that “the eligibility criteria do not ensure that only people who are about to die are allowed on to

the pathway. For instance, patients with dementia, in whom dying can take years, and those who are bed-bound and unable to swallow may be eligible.” He concludes “Deep Continuous Sedation (appropriate only in the last hours or at most days) may replace euthanasia.”

Dr Peter Millard, who with several eminent colleagues wrote to the Daily Telegraph earlier this month about the LCP noted that it “could be seen as

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backdoor euthanasia” and that from 2007-8 16.5% of deaths in UK hospitals came about as a result of “terminal sedation.” This is extremely worrying.

Meanwhile, two very well known older British women have recently spoken out promoting death for elderly people. Joan Bakewell, has been appearing on TV for as long as I can remember in the guise of an arbiter of moral problems, and has now appointed the Government’s “Voice of Older People” while Baroness Mary Warnock, is usually, and erroneously dubbed “our best known ethicist.”

They have called not for the *right* to die, but for the *duty* to die for those who have dementia, and who they claim are a burden on their relatives, or indeed “on the National Health Service.”

A measure of the public feeling about the “benefit” of assisted dying to sick and disabled people is a recent comment in a

local newspaper’s “Your Say” column, which said “Debbie Purdy is proof that regardless of your circumstances, you can remain positive.” If it is considered “positive” when we want to die, are we to be regarded as negative cowards if we want to live? The answer resounds in our ears.

All these frightening developments which affect disabled people make us fear for our lives, but this is the only *funny* case I’ve come across, this time from the USA. Joe Erhman, a member of *US Not Dead Yet*, recalled coming round from surgery still delirious from the anaesthetic and hearing the proposal by a hospital staff member that a Do Not Resuscitate order be placed on him. He said:

“I mustered all my strength and screamed out, ‘I’m 30 years old and I don’t want to die!’. Then a nurse came into the room and asked me why I was ‘verbally abusing’ a staff member. I responded that I was doing it verbally because there was nothing in arm’s reach to throw!”

The truth about “unbearable suffering.”

Fear of pain and suffering is the reason why many people feel drawn to favour euthanasia, and because of this it’s important to know that most physical pain can be controlled with good palliative care. In fact, however, the vast majority of requests to be killed are not because of pain but as a result of severe depression which can and should be treated.

The pro-euthanasia lobby claim that euthanasia should be

available for “unbearable and unrelievable pain” which most people think means only physical pain. However, in fact their definition of it is very wide. For instance, Sir Ludovic Kennedy, former President of the UK’s Voluntary Euthanasia Society, has said:

“The patient must be beyond the help of treatment, and find his suffering, physical or mental, unbearable... Nor is it only pain ... which causes people to long for death, but the miserable side-effects which often accompany it – incontinence, vomiting, bedsores, breathlessness, oedema, insomnia – leading to a gradual disintegration of the personality and death without dignity.”

The latest figures from Oregon show that while 95% of patients requested euthanasia or assisted suicide for “loss of autonomy” and 92% for “loss of dignity” only 5% (3 people) requested it for “inadequate pain control.”

I experience all the symptoms he cites apart from bedsores, and have done for many years, so presumably my personality must be well disintegrated by now. Perhaps my friends are too polite to tell me!

Since the pro-euthanasia lobby claims that much physical pain is unrelievable, it is important to know the truth. The latest figures from Oregon show that while 95% of patients requested euthanasia or assisted suicide for “loss of autonomy”

and 92% for “loss of dignity” only 5% (3 people) requested it for “inadequate pain control.” It should be noted here that hospice care is not as well developed in Oregon as in other US states, or the UK.

Although it is possible to reduce consciousness to some extent at the end of life to relieve pain, it must be acknowledged that in ordinary circumstances not all pain can be completely relieved. This is the

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case for me, and I know from my own experience that what is needed is not to be abandoned or presumed to be “better off dead,” or to have one’s worst fears of being “burdensome” confirmed, but rather to be surrounded by those who care. They may not be able to take the pain away, but their presence can be a source of enormous comfort.

However, the propaganda from the pro-death lobby is strong and people who are suffering and lonely have difficulty in ignoring it, and choosing life. We have already seen that the “right” to die is fast becoming the “duty” to die. There have also been many prominent cases of disabled people who have apparently been faced

with the “fact” that they will choke to death. and who have thus been frightened enough to prefer deliberate killing. Some of these people have “chosen” either to campaign for assisted suicide or to go to Switzerland for to die.

The case of Dianne Pretty who had Motor Neuron Disease preceded that of Debbie Purdy, and had some similarities to it. Dianne Pretty had Motor Neuron Disease and wanted an assurance by the Director of Public Prosecutions that her husband would be able to kill her without fear of prosecution since she could no longer do so herself. She failed in this attempt in all the UK courts and finally in the European Court of Human Rights.

One argument she consistently used was that she, like other people with MND would choke to death, and the media actually reported first that she would die in this way, and then that she had actually done so. In fact it was entirely false.

As long ago as 1995 Dr Nigel Sykes of St. Christopher’s Hospice in London noted that of the 300 plus MND patients he had treated *not one* had died of choking. This has also been confirmed by my own local hospice Dr, Richard Sloan also an expert on MND who I spoke to recently. The hospice doctor who actually cared for Dianne Pretty explained that she did not choke to death but sadly the myth has remained strong, and has persisted despite ample medical evidence that it is untrue.

This article is part of the text of a speech given by the author

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References are available on request.