

## **EUTHANASIA & ASSISTED SUICIDE SYMPOSIUM.**

**WASHINGTON D.C. MAY 2009**

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. Often “dying with dignity” is also used to mean a 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 has been legalized, even with supposedly “strict safeguards.”

### **LEGALIZED “VOLUNTARY EUTHANASIA” SPREADS**

Since Holland became the first country to fully legalize euthanasia on 1<sup>st</sup> 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 national guidelines a protocol from Groningen University Hospital<sup>1</sup> allowing for the “mercy killing” of newborn disabled babies, who clearly can’t volunteer! Most of these babies have spina bifida, which 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,<sup>2</sup> and euthanasia deaths have even been shown on TV in an attempt to reassure people that it really is “a good death.”<sup>3</sup> This tactic has also been used in the UK, for the same purpose.<sup>4</sup>

“Voluntary” euthanasia is now legal in Belgium, Luxembourg, Switzerland and the US States of Oregon, Washington and Montana, the latter solely by judicial fiat. And bills to legalize assisted suicide are being debated in several other US states and in countries around the world.

Francine Lalonde, MP has now introduced, for the third time, a bill to legalize euthanasia in Canada. In England and Wales the Coroners & Justice bill could allow UK citizens to legally go to Switzerland for euthanasia with no penalty for relatives who accompany them, and Lord Joffe aims to bring in an assisted suicide bill into the House of Lords for the third time. In the Scottish parliament Margo MacDonald, who has Parkinson’s disease hopes to bring in the End of Life Choices (Scotland) bill at some point in 2009. It will apply to the terminally ill and those with “irreversible disabilities they find intolerable”<sup>5</sup> from 12 years (or younger) upwards.

### **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 legal euthanasia.<sup>6</sup> In some countries, notably the UK and USA, profoundly disabled people and elderly people with dementia are already being killed by withdrawal or withholding of assisted food and fluids. It has also transpired that the deaths of people with less severe learning disabilities are being procured in the UK, even though this is illegal.

---

<sup>1</sup> “Dutch doctors adopt guidelines on mercy killing of newborns” by Tony Sheldon. *British Medical Journal* 16 July 2005

<sup>2</sup> Spanjer M. “Mental suffering as justification for euthanasia in Netherlands.” *The Lancet*. 25 June 1994.

<sup>3</sup> “Dutch euthanasia death” *Sunday Times* 27 November 1994

<sup>4</sup> “Assisted suicide: wife explains husband’s hope for film.” By Matthew Moore. 10 December 2008. Craig Ewart’s death at Dignitas was filmed for Sky TV and shown on British television on the date of this article.

<sup>5</sup> “MacDonald to push ahead with her bid to make assisted suicide legal” by Katrine Bussey. *The Scotsman* 9 December 2008

<sup>6</sup> Oliver, D. and Fisher, J. “Assisted suicide is not always as easy as suggested.” *BMJ* 2002; 324:846

The parliamentary and health service ombudsman in the UK recently issued a report called “Death by Indifference” based on a campaign by Mencap, a charity for people with learning disabilities. This cites six examples of unequal or discriminatory treatment leading to the deaths of people with learning disabilities in UK National Health Service hospitals.<sup>7</sup>

Meanwhile the so-called “Liverpool Care Pathway” in the UK, and the new guidelines produced by the General Medical Council, force doctors to withdraw or withhold food and fluids from vulnerable people whether or not they are actually dying.<sup>8 9</sup> Doctors can be prosecuted for saving a life, if the patient *refused* treatment in advance, but patients can be overruled by doctors if they *request* treatment, particularly assisted food and fluids.<sup>10</sup>

Simultaneously, two very well known older British women have recently spoken out: Joan Bakewell, who has been appearing on TV for as long as I can remember in the guise of an arbiter of moral problems, and who has now appointed the Gvts “Voice of Older People” and Baroness Mary Warnock, supposedly 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.”<sup>11 12</sup>

All these discriminatory developments against disabled people are worrying, 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!<sup>13</sup>

<sup>7</sup> “NHS patients ‘died of neglect’ by Sarah-Kate Templeton. *Sunday Times* 22 March 2009

<sup>8</sup> National Health Service End of Life Care Programme leaflet. May 2008

<sup>9</sup> “Doctors to be struck off if they do not listen to dying patients.” By Rebecca Smith. *Daily Telegraph* 26 March 2009

<sup>10</sup> Press Release: “Right to Life case – Leslie Burke appeal rejected by European Court of Human Rights” *Irwin Mitchell Solicitors* 8 August 2006

<sup>11</sup> “The right to die: Can there ever be such a thing as a ‘good death’” by Paul Vallely *Independent* 6 December 2008

<sup>12</sup> “New ‘Voice for the Elderly’ reveals euthanasia beliefs” *The Christian Institute* 18 November 2008

<sup>13</sup> “Not Dead Yet” by Nat Hentoff. *The Village Voice*. September 1996

A glimmer of hope comes from a recent poll in the UK which found that only 34% of doctors favor euthanasia and 35% favor assisted suicide, but it is salutary to note that, asked the same questions in the same poll 82% and 62% of the general public favor death for vulnerable people.<sup>14</sup> I hope, but am not confident, that this simply indicates of lack of understanding about the realities of life with a disability, which could be remedied, rather than being an example of eugenic thinking, which is all too common in pro-euthanasia circles.

In the UK No Less Human, the group I run for disabled people, their families and care givers, and Not Dead Yet UK, ALERT and the umbrella organization Care not Killing work well together. However, we will have to work much harder to oppose more bills and initiatives allowing direct killing. We need to encourage the silent majority of disabled people who don't want euthanasia legalized to speak out, and help those who want to die to re-establish a sense of their own value as unique human beings. In all this we clearly have an uphill task, but our very lives are threatened if we don't.

### **THE TRUTH ABOUT “UNBEARABLE SUFFERING”**

Fear of pain and suffering is the reason why many people feel drawn to favor euthanasia, and because of this it's important to know that most physical pain can be controlled in the right environment. 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, President of the UK group “Dignity in Dying”, formerly known as the 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.<sup>15</sup>

---

<sup>14</sup> “Majority of doctors opposed to assisted suicide” by Sarah Boseley. *The Guardian* 24 March 2009

<sup>15</sup> “Why, after 45 years, I can no longer support the Liberal Democrats” by Ludovic Kennedy. *The Times* 19 May 2001

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.”<sup>16</sup> And 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 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.

## **SUICIDE TOURISM IN SWITZERLAND**

Although “assisted suicide” was made legal in Switzerland as long ago as 1941, it is only in more recent years that non-Swiss people have been allowed to go there to be killed by assisted suicide. 100 people from Britain have travelled to suicide clinics abroad since 1992, the most famous being “Dignitas” in Zurich, founded and run by Dr. Ludwig Minelli, which has killed about 1,000 people. Dr. Minelli believes there should be no restrictions on who is killed, and has said that assisted suicide should be available “on demand.”<sup>17</sup> He is currently going to the Swiss courts to allow Dignitas to go ahead with the killing of a “healthy” Canadian woman who simply wants to die at the same time as her terminally ill partner.<sup>18</sup>

None of the relatives and so-called “friends” who have accompanied dying or disabled or sick people to Dignitas has ever been prosecuted, nor will they ever be, if the Coroners & Justice bill in the UK becomes law in its current form.

---

<sup>16</sup> 2008 Summary of Oregon’s Death with Dignity Act, released on 3 March 2009.

<sup>17</sup> “Suicide on demand for the healthy: ‘Its a marvellous possibility’ for all says Dignitas boss” by Steve Doughty. Daily Mail 3 April 2009

<sup>18</sup> “Dignitas defends assisted suicide” *BBC News* 1 April 2009

Jane Campbell, a disabled member of the British House of Lords, and founder of Not Dead Yet UK has said "... [the Crown Prosecution Service] has got to start prosecuting, otherwise it sends out a message that it's OK to help people die."<sup>19</sup>

Interestingly, although Dignitas is meant to be a "not for profit" organization Dr. Ludwig Minelli has so far failed to hand over his books to the police. He is reported to have become a millionaire by "assisting" the killing of vulnerable people.

One of the latest who succeeded in his wish to die at Dignitas was Daniel James aged 23 from the UK, who died there on 12 September 2008. He had been a promising rugby player, but was paralyzed from the chest down in a training session in March 2007. He was not terminally ill, but had not yet been able to adjust to his disability.<sup>20</sup>

Many disabled people in the UK including members of No Less Human and Not Dead Yet UK spoke out in an attempt to try to persuade Mr. James and other disabled people not to take the route of death but to be helped to live. But the propaganda from the pro-death lobby is strong and people who are suffering and lonely have difficulty in ignoring it, and choosing life.

One such instance is that of Dianne Pretty, a lady with Motor Neuron Disease (aka Lou Gehrig's Disease) who lost her case in several courts to guarantee non-prosecution of her husband, should he "help her die." The media, prompted by "Dignity in Dying"(formerly the UK Voluntary Euthanasia Society) claimed first that she would inevitably die from choking" and then that she actually had died in that way.<sup>21</sup> It was all lies, as hospice doctors who cared for her attested, but the lie has remained strong, and persists to this day.

## **ATTEMPTS TO LEGALIZE EUTHANASIA IN THE UK**

A recent attempt to legalize assisted suicide in the UK was the "Assisted Dying for the Terminally Ill" bill sponsored by Lord Joel Joffe, a South African "human rights" lawyer who previously worked with Nelson Mandela. The bill was defeated in 2006 after massive lobbying by Care Not Killing, No Less Human, Not Dead Yet UK and other groups. At the time of his losing the bill Lord Joffe claimed he would not again bring forward such a bill.

<sup>19</sup> *Community Care*. 15 January 2009

<sup>20</sup> "Rugby star Dan James in 'assisted suicide' after training injury" by David Brown. *The Times* 18 October 2008

<sup>21</sup> Debbie Purdy's wish to die" *Sunday Telegraph* 15 June 2008.

However, he recently reneged and said that he did after all intend to try yet again to bring forward such a bill. He was supported by Patricia Hewitt, a Member of Parliament who thinks assisted suicide should “of course” be legal in the UK.<sup>22 23</sup>

On 5<sup>th</sup> 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 patients. 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” in a vain attempt to persuade us that it was all entirely benign

Suffice it to say the change of name didn’t allay our fears. 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<sup>24</sup>

The latest attempt to change the law in the UK, which is still ongoing, is being made by Debbie Purdy, a woman who has primary progressive multiple sclerosis. She is attempting to “clarify the law” on assisted suicide, so that if she goes to the Dignitas clinic in Switzerland to die, her husband will not be prosecuted for accompanying her. She lost her case in the High and Appeal courts, and has now been given permission to appeal to the House of Lords, the highest court in the UK.<sup>25 26</sup> Mrs. Purdy made a very telling comment about her views on the value of terminally ill people after losing her first judicial review. She said: “We are not asking for the law to be changed for it to be made compulsory for people at the end of their lives to be dragged off to the knacker’s yard (an unsavoury place where in the past unwanted or worn out horses were “put down.”). But [she says] this should be one of the choices...”<sup>27</sup>

---

<sup>22</sup> “The ‘right to die’ is a fashionable nonsense” by Dominic Lawson. *Sunday Times*. 14 December 2008

<sup>23</sup> Why Patricia Hewitt is fighting for the right to die with dignity” by Helen Rumbelow. *The Times* 21 March 2009

<sup>24</sup> “New treatment guidelines mean doctors must follow wishes of terminally ill patients” by Steve Doughty. *Daily Mail* 7 March 2009

<sup>25</sup> “Woman loses assisted suicide case.” *BBC News* 19 February 2009

<sup>26</sup> “Bradford woman continues assisted suicide fight” *Bradford Telegraph & Argus*. 3 April 2009

<sup>27</sup> “Debbie Purdy demands Director of Public Prosecutions spell out law on assisted suicide. By Martin Beckford. *Daily Telegraph* 3 October 2008

## **A PERSONAL EXPERIENCE**

Perhaps the most compelling argument I can present is my own experience. I have suffered a lot of pain throughout my life, and now need increasing doses of morphine, but even that doesn't always alleviate the pain. In addition to spina bifida and hydrocephalus, and using a wheelchair full time, I also have emphysema, a breathing problem that makes me susceptible to chest infections, arthritis, lordosis and kyphoscoliosis – causing my spine to twist out of shape in every possible direction, and osteoporosis – brittle bones, which has caused my spine to collapse and trap nerves. When the pain is at its worst I can't move or think or speak.

Earlier this year I experienced alarming and very frightening mental symptoms, which turned out to be due to excessive doses of morphine. I was given a stark choice – take the extra morphine and live with the mental symptoms, or take less morphine, to prevent the mental symptoms, but increase the physical pain. I chose the latter, preferring physical to mental pain, but it is certainly a tough road to cope with unending and severe physical pain, which I have been assured will inevitably get worse.

About 20 years ago pain of various sorts compounded to made me feel I wanted to die. At that time, doctors believed that I did not have much longer to live. Over time, my desire to die became a settled wish and it lasted about ten years. During the first five of those years I attempted suicide several times.

A few of the times were really “cries for help.” I became ingenious at finding ways of hurting myself to add to my already severe spinal pain. My friends went through the house removing sharp objects (I can clearly remember through the mental haze eating scant meals with a spoon because all the knives had been moved), but then I would use pins, needles, even paper clips and sharpened pencils to open up the scars on my wrists caused previously by slashing them with a knife.

Some of the attempts, however, were serious and I tried various methods: large overdoses of various drugs and cutting my wrists seriously. I was determined to succeed then, especially on one occasion I particularly remember. I had taken a large overdose of painkillers and cut my wrists badly with an old rusty penknife which had escaped the general removal of sharp objects.

I then drank a whole bottle of Martini, lay down in bed, cuddled my favorite teddy bear and waited to die. Fortunately for me (at the time I thought most unfortunately) my friend Sue arrived shortly afterwards.

My door was never locked at that time and she let herself in, found I was losing consciousness and called the emergency services. I was taken to hospital and treated against my will. The doctors waited until I lost consciousness then treated me anyway. If euthanasia had been legal then, I would have requested it with no hesitation at all, and if Living Wills had been legally binding, I would certainly have written one, refusing all life saving treatment. I would have satisfied all the supposedly “strict criteria” which pro-euthanasia groups want, and which are mandatory in places where euthanasia or assisted suicide is legal.

It took my friends, and particularly Colin, my full time assistant, who is also speaking here,, many years to persuade me that my life did have value. Their efforts and a trip to India in 1995, during which I met with disabled children, who I later began to support financially, helped to turn my life around. After that trip I said to Colin “Do you know, I think I want to live.” It was the first time I had thought that for over ten years.

Had euthanasia or “assisted suicide” been legal I would have missed the best years of my life. And no one would ever have known that the future held such good times, and that the doctors were wrong in thinking I didn’t have long to live.<sup>28</sup>

Some years ago I read a booklet by a young British medical doctor, James Casson, who was dying of cancer. He titled his book “Dying: The Greatest Adventure of my Life.”<sup>29</sup> I think there is also a place for a book entitled “Living: The Greatest Adventure of my Life.” My life has been full of pain and suffering, true. But it has also been one long adventure, with great highs and great lows. I think my eventual death will also be an adventure – but for now I’m content to wait for that particular adventure to come naturally, in its own time.

ALISON DAVIS. May 2009

---

<sup>28</sup> It is not unusual for doctors predictions about life expectancy to be wrong. For instance Baroness Ilora Finlay, a hospice doctor, cites one case of a cancer patient still alive 18 years after a terminal prognosis, when he asked for euthanasia, in “*Assisted Suicide is fine in a perfect world. We don’t live (or die) in one*” The Times 1 April 2009

<sup>29</sup> “Dying: The Greatest Adventure of My Life” by James H. Casson. Christian Medical Fellowship Publications. 1986