

“NEVER AGAIN”

REPORT ON THE SECOND INTERNATIONAL SYMPOSIUM ON EUTHANASIA AND ASSISTED SUICIDE

**Lansdowne, Virginia
May 29-30, 2009**

Catholic Organization for Life and Family

June 16, 2009



The Second International Symposium on Euthanasia and Assisted Suicide was held near Washington DC, in Lansdowne (Virginia), on May 29-30, 2009. It was preceded by a Strategy Meeting (May 28) attended by 38 leaders of groups opposed to euthanasia and assisted suicide.

Both events were organized by Mr. Alex Schadenberg, executive director of the Euthanasia Prevention Coalition (Canada) and chair of the International Euthanasia Prevention Coalition, and co-sponsored by EPC, Not Dead Yet (USA), Physicians for Compassionate Care (Vermont), Care Not Killing (UK), No Less Human (UK), The Compassionate Health Care Network (Canada), the International Task Force on Euthanasia and Assisted Suicide Terri Schiavo Foundation (USA), ALERT (UK) and the Institute for the Study of Disability and Bioethics (USA).

During two full days, some 140 participants heard some of the most prominent experts on these critical issues and discussed among themselves the most effective arguments and strategies developed to counter the world-wide, extremely well organized, pro-euthanasia / pro-assisted suicide lobby. It soon became obvious that “our struggle is not against flesh and blood, but against the rulers, against the authorities, against the powers of this dark world and against the spiritual forces of evil in the heavenly realms” (Eph. 6:12). This is truly spiritual warfare.

The following were the conference themes:

- *Where we are – The history to the present*
- *Palliative Care – Current issues*
- *The Washington I-1000 assisted suicide Initiative*
- *Recent campaigns and experiences*
- *A personal story*
- *Culture change and culture shift*
- *Euthanasia by dehydration – real stories*
- *The disability perspective*
- *The fear of suffering*
- *Working together*

Among the participants were lawyers, physicians, nurses, hospice consultants, pro-life movement representatives, university professors, specialists from the disabled community, activists, journalists, members of the clergy, diocesan representatives, students and two delegates from the pro-euthanasia/assisted suicide lobby. They also heard the personal stories of people living with disabilities or accompanying loved ones living with a disability.

This event was a privileged occasion to network with people from other countries where assisted suicide and euthanasia are already legalized.

Reviewing all presentations would have made this report excessively long. We have instead identified some of the main ideas gathered from certain presentations and from conversations with the speakers which appear to be the most appropriate in our cultural context. For more clarity, we will present them in point-form format.

LATEST DEVELOPMENTS IN THE UNITED KINGDOM

Dr. Peter Saunders, MB, FRACS, is the General Secretary of the Christian Medical Fellowship and the Director of the Care Not Killing Alliance, United Kingdom.

- In the United Kingdom, assisting suicide is a crime and intentionally killing is also a crime. In 2005, the Mental Capacity Act made advanced directives legally binding.
- In its February 17, 1994 Report, a House of Lords Select committee recommended:
 - No change in the law to allow euthanasia
 - Competent patients may refuse treatment
 - Development of Palliative Care Services
 - Research into pain relief and symptom control
 - Treatment-limiting decisions *not* to be determined by resource availability

Lord Walton of Detchant explained: *“We concluded that it was virtually impossible to ensure that all acts of euthanasia were truly voluntary and that any liberalisation of the law in the United Kingdom could not be abused. We were also concerned that vulnerable people - the elderly, lonely, sick or distressed - would feel pressure, whether real or imagined, to request early death.”*

- Between 2003 and 2005, Lord Joffe introduced three bills. The first ran out of time; the second led to Lords’ Select Committee Reports; and the third came to the vote.
- Faced with the 2006 Assisted Dying Bill, which promoted assisted suicide but not euthanasia (including nurses’ involvement and worrying definitions, e.g. “terminally ill” and “unbearable suffering”), disability rights groups, professional groups, healthcare providers, pro-life groups, faith based organisations and concerned individuals got together and formed an alliance: *Care Not Killing*. It took six months to do so. The Catholic Bishops Conference, the Church of England and the Christian Medical

Fellowship were involved from the beginning and provided the 12 000 pounds necessary to launch this initiative.

- Care Not Killing membership comprises 18 core organizations and 30 associate organizations. Among its core members are: ALERT, the Association for Palliative Medicine of Great Britain & Ireland, the United Kingdom Disabled People's Council, CARE, the Catholic Bishops Conference of England and Wales, the Catholic Union, the Christian Medical Fellowship, the Church of England, the Evangelical Alliance, the Heythrop Institute, the Lawyers' Christian Fellowship, LIFE, the Northern Ireland Hospice Association, RADAR and Right to Life.
- All these partners, and many more who often do not share the same views on abortion or other divisive issues, agree on three common aims:
 - Promoting more and better care (palliative care)
 - Opposing assisted dying
 - Changing public opinion

Their common strategy includes:

- A website – www.carenotkilling.org.uk
 - A powerful slogan – “Care Not Killing”
 - Resources – leaflets/DVDs/papers
 - Spokespeople
 - Evidence-based research
- Launched on January 30, 2006, Care Not Killing distributed 500,000 leaflets, 15 000 copies of the DVD “Doctors speak on assisted dying”, participated in a major public debate against Dignity in Dying, organized a petition and a major letter writing campaign to Peers and MPs, and a major media campaign (patients, doctors and disabled people spoke out against the bill; faith leaders united; demonstrations were held outside parliament and peers turned out in force to oppose the bill. It was defeated by 148-100 at second reading on May 12, 2006.
 - On June 29, 2006, the British Medical Association voted overwhelmingly to oppose euthanasia: 65% against voluntary euthanasia, 65% against physician assisted suicide, and 94% against non-voluntary euthanasia.
 - At the present moment, the law remains unchanged and the medical profession is united against euthanasia and assisted suicide, though public opinion polls remain in favour of a change in the law. Dignity in Dying has regrouped (12 staff and over £1million turnover) and is promoting advance refusals, more well-funded court cases and physician assisted suicide as part of “end of life care”. They are using more spokespeople and celebrity support, and promoting high profile “Dignitas” suicides.

- Care Not Killing's strategy includes:
 - Highlighting those more extreme agendas
 - Highlighting positive role models
 - Highlighting abuses in Oregon and the Netherlands
 - Emphasizing small numbers and public safety issues
 - Lobbying within Parliament
- For the media, Care Not Killing has become the reference. It is a Limited Liability Non Charitable Company and its five directors meet every two months. Core organization representatives sit on Its Advisory Board to develop strategies.

OREGON UPDATE – AN EROSION OF CONSCIENCE

Dr. William Toffler, MD, is Professor of Family Medicine and National Director of Physicians for Compassionate Care in Portland (Oregon).

A review of the status of assisted suicide in Oregon shows that

- The Oregon “model” legislation is seriously flawed (despite shroud of secrecy)
- It has had an impact on national and international events
- There has been an erosion of traditional medical ethics and trust
- Conscience protection has emerged as a critical front

An academic review of six cases (Hendin H, Foley K. Physician assisted suicide in Oregon: a medical perspective. Mich Law Rev 2009;106: 1613-45) reveals:

- The failure to ensure palliative care alternatives
- The inadequacy of “safeguards”
- An emphasis on protecting physicians
- Deviation from accepted medical practice
- Inadequate monitoring

So why say no to assisted suicide?

- It is dangerous for patients
 - *Pressures due to health care costs*
 - *Fails to protect depressed or mentally ill*
 - *Families can be left out, not notified*
 - *No oversight of quality of patient care*
- Advocates want to expand the law

Many pressures and fears are based on Health Care costs...

- Limits on healthcare spending
 - *OHP won't pay for chemo, radiation, surgery if the patient's survival is estimated less than 5 years*
 - *BUT will pay for assisted suicide as “comfort care”*

- Most expensive time of life is expendable
- Expensive life is not as “worthy”
 - *Disabled adults are concerned*
 - *Some disabled newborns euthanized in Holland*

The Founder of the Hemlock Society (now Compassion and Choice), Derek Humphry, clearly said that “*Physician-assisted Suicide and Euthanasia can help solve the problem of rising health care costs*” (12/2/1998).

Pain is not the reason for suicide according to Oregon family members. No physical symptoms were rated higher than 2 on scale of 1-5

- The most important reasons are:
 - wanting control over circumstances of death
 - fear of loss of dignity
 - preferring to die at home
 - concerns about independence, ability for self care and quality of life

Depression is untreated...

- Depressed or mentally ill persons are considered “**competent**” unless they have an “**impaired judgment**”
- The word “capable” is used on Oregon doctor forms to describe a person who “has the ability to make and communicate health care decisions to health care providers, including communication through persons familiar with the patient’s manner of communicating, if those persons are available”
- Mental health referrals are not required

The Oregon model has:

- Legalized a “shroud of secrecy”
 - Doctors are required to *falsify the death certificate* (Sec. 4 (l)(ii)(B)(2) by listing the underlying terminal disease as the cause of death
 - Administratively required documentation regarding compliance is collected, but the information may not be made available for inspection by the public (Sec. 15)
- Institutionalized bad medical practice where
 - Focus shifts away from relieving distress
 - There is no peer review or medical quality oversight
 - The absence of medical standards means that doctors who participate “*in good faith*” **cannot** be: disciplined for bad practice (lose their license), expelled from their job, medical organization, or business relationship, be criminally prosecuted (sent to jail) or sued for medical malpractice

So-called “death with dignity” has become death on demand:

- The right to choose death when you want it becomes the right of other people to choose for you when you are unable
- Autonomy and control by a few becomes abuse of the vulnerable many
- The plan for use in exceptional circumstances becomes death on demand and the elimination of “worthless undignified lives.”

Because the proponents of assisted suicide have been very careful, the reported evidence does not show strong empirical evidence of a slippery slope. But the Barbara Wagner story confirms the slippery slope argument... She was a 64 year old retired school bus driver and her metastatic lung cancer was back after 2 years remission. Her oncologist prescribed chemotherapy to slow cancer growth, reduce symptoms and extend her life. Barbara received a letter from the Oregon Health Plan saying that chemotherapy was not covered, but ...assisted suicide drugs were 100% covered! (*Eugene Register-Guard*, June 3, 2008).

Choice for physicians is under attack as they are being told that exercising their right of conscience might “constitute an imposition of religious or moral beliefs on patients” (ACOG Committee on Ethics Opinion No. 385: Nov, 2007).

- The patient’s well being is paramount
- Where conscience causes physicians to “deviate from standard practice”, they must give “prior notice” to patients
- They have a duty to refer in a timely manner
- In “emergency” cases, they need to provide care regardless of their personal moral objections
- In “resource poor areas”, the law insists that “providers...should practice in proximity to individuals who do not share their view...”

THE WASHINGTON I-1000 ASSISTED SUICIDE INITIATIVE

Margaret Dore is an attorney in the Seattle area. She was admitted to practice in 1986 and represents clients in guardianship, probate and trust matters. She is the immediate past chair of the Elder Law Committee of the ABA Family Law Section.

Because of her preoccupation regarding elder abuse, she has studied many pro-euthanasia and pro-assisted suicide bills and has come to the conclusion that they essentially all say the same thing. Here is the overview she presented at the symposium:

- The Death with Dignity Acts are STATUTES.
- The first issue is therefore, what do they say? Moreover, all of them say essentially the same thing:
 - They are closet euthanasia bills. The new Canadian bill (C-384) is the exception, which is upfront about being a euthanasia bill. With

the American versions, you can't call it euthanasia because euthanasia, mercy killing, etc. are defined out of the statutes.

- The bills have relaxed competency requirements so that it's easier to get people signed up.
 - The bills specifically allow behavior that allows a patient to be coerced by other people.
 - Liability for the actions of other people is generally illusory.
 - Once the person is signed up, no more patient consent is required despite proponents' representations to the contrary. Patients have a right to revoke the prior request, but this is not consent. An incompetent, sedated or sleeping patient would not have the ability to revoke a prior request.
 - Overall, the statutes are a fraud and/or "choice" is a lie.
- Conclusion: Death with dignity Acts are not about dignity and choice. They are about enabling people to pressure others to an early death or even cause it. They also encourage patients with years to live, to give up hope.

"CULTURE CHANGE AND CULTURE SHIFT"

Wesley Smith (USA) is a senior fellow at the Discovery Institute, an associate director of the International Task Force on Euthanasia and Assisted Suicide, and a special consultant for the Center for Bioethics and Culture. He left the full time practice of law in 1985 to pursue a career in writing and public advocacy. His book *"Forced Exit: The Slippery Slope from Assisted Suicide to Legalized Murder"* (1997) has become a classic in anti-euthanasia advocacy.

Here are some of the points he made in his presentation:

- Health has become the primary good in society today. The defining ends of society are now no longer justice, equality and mutual caring, but that no one should suffer. We have become paralyzed by the fear of suffering. When society's first goal is quality of life and making sure that no one suffers, the principles of right and wrong no longer matter. Some may decide that others' best interest is to die.
- With the collapse of moral judgment and critical thinking in society, we need to get involved to help depressed people wanting to die. We need to become once more a caring and compassionate society. We must not allow abandonment, but work to alleviate the suffering. This takes time and effort.
- The solution is hospice care and pain control. The power of palliative care, the power of love and the power of compassion are immense.

- Our role as a human race is to get a person from the “I want to die” stage to the “I’m ready to die” stage.
- People are victimized by the assisted suicide movement; they kill the sufferer and create suffering. We have a better way: LOVE and COMPASSION... BEING WITH...

THE DISABILITY PERSPECTIVE (1)

Diane Coleman (USA) is a person with significant disabilities and the Founder and President of “Not Dead Yet”, a grassroots disability rights organization opposing euthanasia and assisted suicide. It is a secular, single issue group.

- The central themes and messages of this organization are that:
 - The medical system resists accountability
 - Financial constraints pose a threat in the medical system
 - Bias against people with disabilities permeate society and medical providers
 - Fear of disability drives pro-euthanasia advocacy
- A central demand of the disability rights movement is: “NOTHING ABOUT US, WITHOUT US”
- What does disability have to do with assisted suicide? The disability experience is that people who are labeled “terminal,” based on a medical prediction that they will die within six months, are — or almost inevitably will become — disabled.
- “When patients ask for death to be hastened, the following areas should be explored: the adequacy of symptom control; difficulties in the patient’s relationships with family, friends, and health workers; psychological disturbances, especially grief, depression, anxiety,” (Block SD; Billings JA, Patient requests to hasten death. Evaluation and management in terminal care. Archives of Internal Medicine. 154(18):2039-47, 1994 Sep 26).
- “The desire for euthanasia or assisted suicide resulted from fear and experience of two main factors: disintegration and loss of community. These factors combined to give participants a perception of loss of self. . . . Symptoms and loss of function can give rise to dependency on others, a situation that was widely perceived as intolerable for participants: ‘I’m inconveniencing, I’m still inconveniencing other people who look after me and stuff like that. I don’t want to be like that. I wouldn’t enjoy it, I wouldn’t, I wouldn’t. No, I’d rather die.’

“Participants frequently used the notion of dignity to describe the experiences associated with disintegration: . . . ‘You’ve become a bag of potatoes to be moved from spot to spot, to be rushed back and forth from the hospital, to be carried to your doctors’ appointments or wheeled in a wheelchair, and it really does take away any self-worth, any dignity, or any will to continue to live.’

“. . . Loss of community entailed the progressive diminishment of desire and opportunities to initiate and maintain close personal relationships, owing to loss of mobility, exclusion and alienation by others, and self-isolating actions by participants. . .” Lavery, J.M., Boyle, J., Dickens, B.M., Maclean, H., & Singer, P.A. (2001). Origins of the desire for euthanasia and assisted suicide in people with HIV-1 or AIDS: A qualitative study. *Lancet*, 358 (9279), 362-7.

- “These are quintessential disability issues, and your disability *amici* are here to say that these feelings are not inevitable, that their causes can be successfully addressed and that, most importantly, these emotions do not justify a lethal response.” (from the Not Dead Yet Amicus Brief in the Montana Case).
- In 1997, the National Council on Disability (USA) issued a declaration titled “Assisted Suicide: a Disability Perspective” which was reissued in 2005. It states that “Current evidence indicates clearly that the interests of the few people who would benefit from legalizing physician-assisted suicide are heavily outweighed by the probability that any law, procedures, and standards that can be imposed to regulate physician-assisted suicide will be misapplied to unnecessarily end the lives of people with disabilities At least until such time as our society provides a comprehensive, fully-funded and operational system of assistive living services for people with disabilities, this is the only position that the National Council on Disability can, in good conscience, support.”

The following excerpts from the Not Dead Yet Amicus Brief in the Montana Case illustrate more preoccupying trends...

- “Assisted suicide advocates use the term ‘death with dignity’ to justify assisted suicide, but when asked what ‘indignities’ concern them, they invariably describe the need for assistance in daily activities like bathing and toileting, and other disability realities, as reasons everyone should accept for setting up a societal double standard for who gets suicide assistance while everyone else gets suicide prevention. Like derogatory racist and sexist language, the equation of disability and indignity is anti-disability, or ‘able-ist,’ thinking. Not surprisingly, these negative assumptions are sometimes shared by people whose disability status has not been life-long, but has been acquired by traumatic accidents and

chronic diseases. However, people with disabilities rate our own quality of life as high or higher than the general public rates their own.”

- “By asserting that it is irrational for a non-disabled person to end his or her life, but rational for a disabled person to do so, the law assumes that the non-disabled person’s life is intrinsically more valuable and worthwhile than a disabled person’s life. For *amici*, perhaps no other attitude strikes closer to the heart of the disability civil rights movement. Central to the civil rights of people with disabilities is the idea that a disabling condition does not inherently diminish one’s life; rather, surrounding barriers and prejudices do so.”
- “Providing assisted suicide only for people with disabilities and denying them suicide prevention services, based on a doctor’s prediction of terminal status or other justification, violates the ADA because the presence or absence of disability determines whether state and local governments:
 - enforce laws requiring health professionals to protect individuals who pose a danger to themselves;
 - respond to expressions of suicidal intent in people with disabilities with the application of lethal measures that are never applied to people without disabilities;
 - investigate and enforce abuse and neglect and homicide statutes in cases reported as assisted suicides.”
- “At issue is nondisabled peoples’ intense fear of becoming disabled. When a person with a disability states a desire to die, nondisabled people believe the request is reasonable because they project their own biases and believe that living with a severe disability is a life of dependency, indignity and helplessness; in short, worse than death. The wish to die is based on the nondisabled view that the primary problem for disabled people is the permanent disability and/or dependence on life aids.”
- “When medical professionals and the media use phrases like ‘imprisoned by her body,’ ‘helpless,’ ‘suffering needlessly,’ and ‘quality versus quantity of life,’ purportedly in a humanistic and compassionate way, they are really expressing fear of severe disability and a very misguided condemnation, ‘I could never live like that.’ Society translates these emotions into a supposedly rational social policy of assisted suicide. Whenever permanent disability is [defined] as the problem, death is the solution.... [T]he wish to die is transformed into a desire for freedom, not suicide. If it is suicide at all, it is ‘rational’ and, thereby, different from suicides resulting from [the same] emotional disturbance or illogical despair [that nondisabled persons face].” (C.J.Gill, Suicide Intervention for People With Disabilities: A Lesson in Inequality, 8 *Issues in Law & Med.* 37, 39 (1992).)

- Finally, here are things people with disabilities know that others spent millions to research about individuals and families:
 - People change their minds about what is acceptable as disease/condition progresses
 - Family members don't consistently or correctly predict individual choices
 - Family members have conflicts of interest and project personal disappointments onto their family member
 - Lack of adequate home and community-based services is a big issue
 - Healthcare providers say things to influence/pressure individuals and families to withhold treatment
 - Healthcare providers push public policies to avoid accountability
 - Healthcare providers are not consistently accurate in predicting terminality
 - Healthcare providers devalue people with disabilities and serious health impairments

THE DISABILITY PERSPECTIVE (2)

Alison Davis (UK) runs "No Less Human", a group for disabled people, their families and care-givers which campaigns to achieve the right to life of all disabled people, from conception to natural death. She has spina bifida, hydrocephalus and various other disabling conditions, and uses a wheelchair full time.

Attached is her talk (Annex 1) at the Second International Symposium on Euthanasia and Assisted Suicide. The last section is particularly moving as it is her personal witness.

CONCLUSION

Our country is now facing a third attempt by Bloc Québécois MP Francine Lalonde to legalize euthanasia and assisted suicide: Bill C-384 (*An act to amend the Criminal Code – Right to die with dignity*). Whether it is adopted or not remains to be seen. But one thing is absolutely sure: this issue will not go away. The Canadian pro-euthanasia and pro-assisted suicide lobby is working in close collaboration with the world-wide lobby promoting these deadly practices. Until they achieve their goal, they will not rest.

June 16, 2009

ANNEX 1

ALISON DAVIS : A PERSONAL EXPERIENCE

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 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 national guidelines a protocol from Groningen University Hospital¹ 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,² and euthanasia deaths have even been shown on TV in an attempt to reassure people that it really is “a good death.”³ This tactic has also been used in the UK, for the same purpose.⁴

“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.

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

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

³ “Dutch euthanasia death” *Sunday Times* 27 November 1994

⁴ “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.

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"⁵ 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.⁶ 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.

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.⁷

Meanwhile the so-called "Liverpool Care Pathway" in the UK, and the new guidelines produced by the General Medical Council, force doctors to

⁵ "MacDonald to push ahead with her bid to make assisted suicide legal" by Katrine Bussey. *The Scotsman* 9 December 2008

⁶ Oliver, D. and Fisher, J. "Assisted suicide is not always as easy as suggested." *BMJ* 2002; 324:846

⁷ "NHS patients 'died of neglect' by Sarah-Kate Templeton. *Sunday Times* 22 March 2009

withdraw or withhold food and fluids from vulnerable people whether or not they are actually dying.^{8 9} 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.¹⁰

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.”^{11 12}

All these discriminatory developments against disabled people are worrying, but this is the only *funny* case I’ve comes 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!¹³

⁸ National Health Service End of Life Care Programme leaflet. May 2008

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

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

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

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

¹³ “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.¹⁴ 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,

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

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.¹⁵

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.”¹⁶ 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.

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

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

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.”¹⁷ 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.¹⁸

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.

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.”¹⁹

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.

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

¹⁸ “Dignitas defends assisted suicide” *BBC News* 1 April 2009

¹⁹ *Community Care*. 15 January 2009

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.²⁰

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.²¹ 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.

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

²¹ 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.^{22 23}

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 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 fluids²⁴

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

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

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

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

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.²⁵ ²⁶ 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...”²⁷

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

²⁵ “Woman loses assisted suicide case.” *BBC News* 19 February 2009

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

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

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.²⁸

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.”²⁹ 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.

²⁸ It is not unusual for doctors predictions about life expectancy to be wrong. For instance Baroness Iora Finlay, a hospice doctor, cites one a 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

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

