

A Disabled Person's Perspective on Euthanasia Given at a Conference Organised Jointly by the Society for the Protection of Unborn Children and International Right to Life on 14th March 1998

Introduction

When considering euthanasia; it is also important to look at it from the prospective victim's point of view.

Terminally ill and incurably, severely disabled people as well as the elderly and frail are those most at risk of having their lives deemed "not worth living", whether or not they have actually asked to be killed.

This is an essentially eugenic judgement of vulnerable people by those who say they want only to establish a "right to die" for the terminally ill and incurably disabled. But how can we talk of establishing a "right to die" when everyone is eventually going to die anyway? We need to be quite clear that the "right to die" actually means only that certain sorts of people will be taken at their word when they say they want to die.

Those who promote the supposed "right to die" always say that any euthanasia law should have "strict safeguards" to prevent "abuse of the law". By 'safeguards' they mean requirements such as that:

the person must be terminally ill and/or incurably disabled; have repeatedly asked to die; that two doctors must agree that the person is suffering "unbearably and unrelievably"

There are several points to bear in mind about these supposed "safeguards".

Legal Euthanasia in Holland

In Holland even these 'safeguards' - which actually service to ensure only that people who are generally considered "better off dead" are killed - are regularly ignored. For instance (Scotsman 8/11/95) Dr. Henk Prins killed baby Rianne Kunst, who had spina bifida, because he apparently "could not bear to see her suffer" (i.e. to save his own "suffering"). He killed her by means of a lethal injection and, in a typical attempt to deny the humanity of those with disabilities, Dr. Prins called Rianne a 'sleeping plant'. I suppose in a way this is just a variation on the very commonly heard suggestion that some disabled people are "vegetables" but I wonder at the eminent doctor's apparent botanical expertise in determining exactly the manifestations of the sufferings of plants.

The killing of disabled people in Hollan does not end with babies. National Right to Life NEWS (25/03/97) reported that a three year old Dutch boy with spina bifida "in fair

general condition" was killed by doctors at his parent's request even though a nurse had offered to adopt him. The parents, on being asked why they were requesting euthanasia said their son "did not feel well for a couple of days".

The BMJ (12/07/97) carried an article on "End of life decisions" for mentally disabled people in Dutch institutions (meaning deliberate decisions to hasten their deaths). It transpired that 44% (97 of 222) of their deaths involved such a decision, with only two of the people expressing a wish to die - which in itself needs some explanation.

The article explained that "non-verbal communications" interpreted as a wish to die included the patient removing a feeding tube. I know from personal experience that naso-gastric tubes can be very uncomfortable, and if one was unable to understand the necessity for the tube being in place, it would seem only common sense to try to get rid of the offending object. All these deaths, including three cases of "active euthanasia" of patients none of whom had expressed any wish to die, were reported as "natural deaths".

In practice, then, euthanasia can now be carried out in Holland on the terminally ill, those with incurable physical disabilities, disabled new-borns, the comatose and those in Persistent Vegetative State (PVS), as well as those with mental handicaps and physically health depressed adults - following the case of Dr. Chabot, who killed a physically fit fifty year old woman whose only 'illness' was depression (he called it 'psychic suffering') following her divorce and the death of her two sons.

The findings of the Rummelink Committee in 1991 that there were approx. 1000 cases of euthanasia without explicit request were put into even sharper focus by the official figures for 1995, which showed 3,600 reported cases of euthanasia or assisted suicide, and another 19,000 cases - 19% of all deaths - of doctors ending treatment or administering potentially life-shortening dosages of pain control medicine (Sunday Times 16/03/97). Even the Dutch government admitted 900 cases of euthanasia "without explicit request" per year (Sunday Times 16/03/97).

However, Herbert Hendin, a New York psychiatrist who works in suicide prevention and has spent years studying the situation in Holland claims almost 3,000 cases of euthanasia without request, with other people being cajoled or bullied into seeking euthanasia rather than being given adequate palliative care (Sunday Times 16/03/97).

It is no wonder vulnerable people in Holland are becoming very frightened. A group of severely disabled adults from Amersfoort wrote to the Parliamentary Commission for Health Care and Justice saying, "We feel threatened ... we cost the community a lot ... we are being talked into desiring death" (Hastings Centre Report 02/89).

A letter to the Lancet (2/11/91) revealed that 30% of Dutch cancer patients were refusing to take their morphine or were taking lower doses because they were afraid their doctors were trying to kill them. And a survey of Dutch old people's homes in 11/92 found 3 out of 4 residents afraid they would be killed at some point by a doctor - with or without their consent, (Oracle 22/11/92). Paradoxically some time later it was reported (Washington

Times 5/10/93) that a 'retirement home' was being opened in Holland for circus animals to save them from being 'put down' when they are too old and tired to perform tricks anymore. It seems that the Dutch like to treat animals 'humanely' but not humans!

Threat of Euthanasia to Elderly People

Elderly and ill people have no reason to be afraid here too. A column by Ross Benson who styles himself 'A Man of the World' (Daily Express 3/8/97) expressed strongly pro-euthanasia views saying "a visit to any geriatric ward is a poignant and frightening experience. Here are men and women ... reduced to drooling wrecks. Many have lost their powers of reasoning. They are pitiful and pointless. This is not how any sane person would want to end their life".

As I read this appalling piece, my mind was drawn back to India, a country I know and love, and a Home I visited in Madras a few years ago, run by the Little Sisters of the Poor, where elderly poor people are cared for until they die. In India, the visit of any foreigner is a big event, and I was introduced to the elderly inhabitants as if I were a celebrity. One of the sisters pushed me along the rows of tables where the more physically able residents had just finished their mid-day meal, and all wanted to reach out and shake my hand.

One man particularly caught my attention. Even though I don't speak Tamil, I recognised that his voice was somehow different to the others and he seemed to say only one word. I asked the Sister why. She told me that this man had been 'deaf and dumb' since childhood, and had lived the life of a beggar because it was assumed he was mentally retarded, and thus a 'shame' on the family. He had entered the Home in his late sixties, and there, because the Sisters love their charges, are deeply and individually interested in each of them and want the best for them, his disability was discovered. He was fitted with his first hearing aid at the age of seventy, and was at last being taught to talk - he had just recently learned to say his own name, which was the one word I heard him say. His last years were thus filled with sound and language, something had been denied all his life.

I went into a ward of ladies who were unable to get up, because of physical frailty or because they had what we would call 'senile dementia'. I was pushed up to each bed, and greeted each lady.

I particularly remember two of them. The Sisters smiled as they took me to the bed of their oldest patient, aged 102. She had 'senile dementia' but the Sisters looked at her lovingly and, produced a small bar of chocolate, saying "She loves chocolate and we always keep some for her. You give her a piece and make her happy". I did, and was rewarded by a most beautiful, radiant smile.

Another lady pulled herself up the bed, which obviously cost her much pain and energy. She did this because she wanted a hug. She had tears in her eyes and she reached out with a surprisingly strong grasp, almost pulling me out of my chair. She hugged and

kissed me, always holding tightly onto my hand, and kept repeating one phrase over and over - it turned out to mean, "Have you really come just to see me?"

The difference between these old people, so lovingly cared for, despite very little money available to spend on them, and those in supposedly rich countries who are seen only as 'drooling wrecks' and thought better killed, is profound. And perhaps the lesson of the lady who just wanted a hug is that joyful experiences of human love are not confined to the fit and healthy, who alone are viewed as having lives worth living by those who favour euthanasia.

Killing Disabled Babies in Britain

Negative views leading to killings of vulnerable people also go on here, where euthanasia is supposedly illegal and there is some pressure for them to have the same 'pseudo-legal' status as in Holland. In February 1995, Dr. Richard Nicholson admitted to having killed 2 babies with spina bifida, and the producers of an ITV programme which examined this practice said their research revealed it happened "hundreds of times a year".

On 24/9/97 the Royal College of Paediatrics set out new guidelines on when a child's suffering is thought to "outweigh further benefits of medical treatment". These guidelines included extremely dangerous and worrying provisions for bringing out the deaths of disabled children - for instance the suggestions that children in PVS should have current treatment "withdrawn" (remember 'treatment' can now be defined as food and water) and that treatment could be withheld or withdrawn from other patients who "could survive, but whose residual physical or mental handicap is so great it would be unreasonable to expect them to bear it." It is ironic that the Report's conclusion states that the lives of those who live with severe disabilities, whether physical or mental, are to be highly valued. All who relate to them should offer them the best care, be this "personal, professional or political". I find it quite chilling that a group of eminent doctors could think that bringing about the deaths of disabled people could be compatible with "valuing us highly".

Hospice Care Demonstrates Real Compassion

The film *Death on Request* was shown on British TV in March 1995, and showed the actual killing of Cees Van Der Joode, who had Motor Neurone Disease (MND), by his GP. The doctor maintained that euthanasia was the only way to end his patient's suffering, because death by suffocation was 'inevitable' for patients with MND. Indeed Mr. Van Der Joode made it clear that this was his main worry, and many people must have felt that such a death would be appalling.

The truth, however, was that it need not be so; people with MND can die peacefully and free of pain.

Dr. Nigel Sykes, a doctor at St. Christopher's Hospice in London, has said that not one of the 300 or so MND patients treated by him has ever suffocated. This shows only too clearly the terrible, and false, dilemma presented to Dutch disabled people. They are told the choice is between euthanasia and an appalling painful death. The truth is that with proper palliative care, the choice is between deliberate killing, and a peaceful, pain free death surrounded by those who care and will spare no effort to ensure that they are treated with true dignity.

This truth did not prevent the case of Annie Lindsell, who had MND coming before the High Court in October 1997. It was a totally unnecessary case, which the MND Society - significantly - did not support, and it was funded at least in part by the Voluntary Euthanasia Society, of which Ms. Lindsell was a prominent member. The Court was asked to make a declaration to the effect that her GP would not be acting unlawfully to give her what might prove to be a lethal dose of diamorphine to relieve not pain but "distress" caused by her MND. Much stress was laid on the supposedly 'agonising' deaths people with MND ordinarily suffer from suffocation - a complete travesty of the truth.

On 28/10/97 Annie Lindsell withdrew her case without a declaration having been made. The Judge upheld the well established principle of double-effect, which accepts that doctors may give treatments to bring relief from physical or mental pain or distress (an intended good effect) even if it has the unintended bad side effect of shortening the patient's life, providing the doctor had no intention to kill.

The Judge denied the request of her counsel to 'clarify' the law, and said there was no reason, and never had been any reason, why her doctor should not, treat her, using this principle. In effect, it was acknowledged that the case had been completely unnecessary. This did not stop a generally pro-euthanasia media making the most of her supposed 'victory'. The headlines read "MND woman granted dignified death" and "At last I can die in peace". When Annie Lindsell died on 3/12/97, the headlines were even more excessive and misleading - "She won a landmark court victory to Die With Dignity. Now she has done just that". This was completely untrue. The media seem to really enjoy reporting disabled people who underline their own prejudices that death is preferable to a disabled life. We have a much harder job getting printed reports of the views and activities of members of SPUC Handicap Division - pro-life disabled people, who want to live!

Disabled People Fight Back

Fortunately, however, as well as the SPUC Handicap Division, disabled people in other countries are now being more vociferous in defending their own Right to Life. In the USA, the splendid group Not Dead Yet have organised demonstrations outside the home of Jack Kevorkian, the notorious killer of sick and disabled people, and on 8/1/97 they demonstrated outside the Supreme Court.

Maybe their efforts contributed to the ruling by all 9 Justices of the Supreme Court on 26/6/97 that there was no constitutional right to Physician Assisted Suicide - a great

victory. Mark O'Brien, who has been using an iron lung since 1955 after contracting polio sums up the philosophy of Not Dead Yet when he says, 'I'm not 'suffering', 'terminal' or even 'ill'. Don't waste your pity on me. I want to live!'

Demonstrating clearly what we are up against, another disabled member of Not Dead Yet, Joe Ehman, recalls 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. This sort of order states that if the patient should experience a heart attack or some other life threatening condition which cause his heart to stop beating, he should not be resuscitate. Although in some terminal cases such orders might be appropriate, increasingly they are put on elderly or disabled patients simply because their doctors feel their lives are 'not worth living' anyway.

Mr Ehman describes his response thus: "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!" (Nat Hentoff 9/96). I know I would feel exactly the same way!

In view of Joe Ehman's not unusual experience, and the fact that disabled people in almost every country in the world know very well that doctors have been responsible for the killing of thousands of unborn, disabled babies, as well as, in some places, unknown numbers of disabled infants, it is not surprising that we fear the fact that legalised euthanasia would give doctors wide scope for deciding who they think 'better off dead'. In fact it is inevitable in euthanasia that the power should ultimately lie with the doctor, since he is the only one who can accept or reject a patient's request, or who can label a person 'better off dead'.

Herman Goering, at the height of the Nazi holocaust which, of course, began with the 'euthanasia programme' of the sick and disabled, and went on to encompass 6 million Jews, was heard to say "Who is a Jew is for me to decide".

In similar vein, Dr. Jack Kevorkian, who is known as "Doctor Death" in America after "assisting the suicide" of over 50 people says "any disease that curtails life for even a day is terminal in my book" (USA Today 28/10/92).

He also said, to a Michigan Circuit Court in 1990 "The voluntary self-elimination of individual and mortally diseased or crippled lives taken collectively, can only enhance the preservation of public health and welfare".

So now we know. Perhaps Lewis Carroll in *Alice in Wonderland* summed up all these, philosophies quite neatly: "I'll be the judge, I'll be jury," said cunning old Fury: "I'll try the whole cause and condemn you to death".

Fear of pain and suffering is uppermost in the minds of many people which is largely why the euthanasia lobby's 'strict safeguards' for proposed euthanasia laws, include

allowing euthanasia in cases of 'unbearable pain'. This makes it crucially important that the facts be made clear, not least of which is that most physical pain can be controlled in the right environment (which we will consider later) and that the vast majority of requests to be killed stem from severe depression which can and should be treated. A Canadian University study (Sunday Telegraph 27/8/95), for instance found that most terminally ill patients who want to die are simply suffering from treatable depression and that mental state, not physical pain, most influence the desire to die.

Most importantly, however, we should remember that the 'safeguards' proposed by the pro euthanasia lobby ensure that only those whose lives are considered worthless will be killed. They suggest, in fact, that terminally ill and incurably disabled people are essentially 'right to want to die' while apparently able bodied people are 'wrong' to want to die even though people in both groups may be requesting death equally fervently for much the same reason.

Attempts to Promote Euthanasia in Britain

A particularly worrying tactic of pro euthanasia campaigners is deliberately to confuse the whole issue by claiming they are not really talking about killing at all. For instance, Joe Ashton MP, who brought a Bill on 10/12/97 "to enable a person who is suffering distress as a result of his terminal illness or incurable physical condition to obtain assistance from a doctor to end his life" (defeated 234-89). In the Daily Mail of the same day Mr. Ashton said his Bill was "not about killing people who are suffering without hope of remission, but about patients ending their own lives." This suggests somehow that 'killing' is a dirty word, but 'ending life' is more palatable. The words may be designed to confuse, but the philosophy remains the same and it is the same people who end up dead.

The UK Green paper 'Who Decides' on the Mental Incapacity Bill uses the not dissimilar ploy of pretending that what it is talking about is not really euthanasia at all. In this paper, the Government says they are "firmly opposed to euthanasia" and "have no plans to change the law on euthanasia" and that what they recommend has "absolutely nothing to do with euthanasia". After all this one half expects them to say "and what is more there is no such thing as euthanasia!" Rather more seriously, however, a careful reading of their suggestions reveals that they would enshrine in statute law the Tony Bland judgement which resulted in people in PVS being starved to death, establish Living Wills as legally binding and quite possibly compel doctors to practice a form of euthanasia on the usual victims (the sick and disabled) by deliberate omission. - This interesting example of double-speak is achieved by defining euthanasia so narrowly as "a deliberate intervention with the express aim of ending life" that withdrawing or withholding food and fluids, failure to resuscitate or Do Not Resuscitate orders are excluded from their definition of euthanasia.

The Truth About Relieving Pain

Since pro euthanasia arguments make so much of the "unbearable and unrelievable pain" criterion, it's essential to know and understand the true facts about this. Hospice doctors

estimate that at least 95% of physical pain can be completely and easily relieved (Twycross 7/97) while much of the rest can be relieved by non-drug methods such as TENS machines, acupuncture, even physiotherapy. All this of course, takes time and effort on the part of medical staff - an input which the availability of euthanasia seems to militate against. For instance there are 185 pain clinics in the UK, and only 3 in the whole of Holland. Similarly there are over 250 Hospices in the UK and only 6 in Holland. This may explain the fact that 63% of Dutch people would be opposed to Euthanasia if good pain control could be guaranteed.

When the patient is in pain the doctor's aim should always be to take the least drastic course of action in order to control the pain and this can usually be done - as is desirable - without loss of consciousness. However, in rare cases (usually at the very end of life) it might involve reducing consciousness to some extent.

Of course, we must acknowledge that not all pain can be completely relieved. pain can be made much worse by unresolved fears, worries and anxieties, and it is not only when the patient is viewed as a whole person and not just as a "pain problem" that such concerns can be tackled. Often the main fear is simply that of being alone, and the reassurance of the constant presence of another person who cares, can make all the difference (as I know very well from my own experience, my friends having sat with me, hold my hand and stroked my forehead many a time when my pain - and I do have a lot of pain - has been particularly bad). Instead of according the sick and disabled the dignity of being seen as whole people of infinite value and worth, euthanasia underscores their worst fears of being "useless and burdensome".

We are not, of course, suggesting that suffering be artificially prolonged, as we are sometimes accused of doing (quite the opposite, we want hospice facilities to be extended to all who could benefit from them) nor are we saying that people be required to undergo straightforwardly futile or disproportionately burdensome treatments. What we do say is that the decision to withhold or withdraw treatment should be made not with the intention that the person should die but simply as a result of the observation that the treatment is no longer helpful in dealing with the patient's condition.

The Situation in Australia

The situation in Australia is also very instructive. On 1/27/96 the euthanasia law in the Northern Territories came into effect and its first victim was Bob Dent, age 66, who had had prostrate cancer for 5 years. There are few palliative care facilities available in the Northern Territories and it seems unlikely that Bob Dent got the kind of good quality service available here - the kind that Cicely Saunders, founder of the Hospice movement describes when she says "hospices are not about dying; they are about living until you die". However, perhaps the most important point from the statement he made just before he died is that it was mental rather than physical pain that drove him to request euthanasia (in fact he cited incontinence as his worst problem). In fact, it is widely acknowledged that patients actually experiencing physical pain are less likely to think euthanasia acceptable than those who are depressed and suffering mental pain.

This just goes to underscore what we have already noted - the importance of seeing suffering people as whole, infinitely valuable people, and addressing all the suffering they are experiencing, whether it be physical pain, depression, or a feeling of humiliation from conditions such as incontinence, while always acknowledging their value and worth both to themselves and to others.

I think we need to repeat again and again that physical helplessness is not inherently "undignified". It is only other people's response to it that makes it seem so. What people who feel helpless and a "burden" need to be told is that they are still loved and valued just as much as when they were fit and able, not that they are right to feel so unhappy, and that death is in their best interests.

Happily, the Australian Senate overturned the Northern Territories Euthanasia law by endorsing a Bill introduced by Kevin Andrews MP. Before making their decision the Senate called for submissions from people concerned about euthanasia, and it is instructive that 11,731 of the 12,577 submissions received were totally opposed to the legalisation of euthanasia.

In his speech to the House of Representatives on 28/10/96, Kevin Andrews made a very telling point. He said "if a person is willing to disregard a law which says lethal injections are never allowed, why would they be constrained by a law which says lethal injections are sometimes allowed?"

This really makes clear the inadequacy of the "strict safeguards" euthanasia advocates are so keen to promote.

When considering euthanasia at the request of the patient, we need to be aware that despite what its proponents say, (Bob Dent, for instance, said "If you don't want Voluntary Euthanasia don't have it, but don't deny it to me) it cannot be a legal vacuum - legal killing ultimately affects all the weak and vulnerable.

The UN Declaration of Human Rights says that States have an obligation to protect and secure the inalienable rights of citizens to life and liberty, inalienable rights being those of which I may not be deprived, and of which I may not even deprive myself. Applied to euthanasia this means that it must be wrong to make it legal because if some are allowed voluntarily to give up their right to life, they not only deny their own infinite human value but others, particularly other weak and vulnerable people are likely to have their lives taken too.

Persistent Vegetative State and Euthanasia

Euthanasia is already going on in this country, almost always involving people who are ill or disabled, including the deaths from starvation and dehydration of those in PVS.

Tony Bland was the first adult in this country for whom euthanasia was legally permitted. In order to justify his killing he, was constantly dehumanised by being referred to as if he were essentially already dead. For instance Sir Stephen Brown, the High Court Judge who ruled that Tony Bland could be starved to death that "his spirit has left him and all that remains is the shell of his body". Quite how he could so confidently pronounce on the absence of a human being's "spirit" was never made clear, but his presumptuousness is more than plain. Tony Bland was killed simply because his condition made him the kind of person generally regarded as "better off dead", because he was costing the state money to keep alive, and because it distressed his parents to see him like that. There have been at least 13 such deaths since his, and despite the fact that the Courts maintained the PVS was the "sticking point" for starvation two of these 13 patients - identified only as Miss D and Miss H - were recognised as not in fact in PVS.

The reality is that there is much confusion about the ethics of starving PVS people to death, a confusion noted by Paul Wainwright, Chair of Royal College of Nursing (RCN) Ethics Committee who (Sunday Telegraph 7/7/96) points out the inconsistency between claiming that the patient has "no sensation or feeling" and "is not really there" and the simultaneous and inconsistent claim that 'letting them die' is in their own best interests to "prevent further suffering and indignity". The inconsistency is clear - if they can "feel nothing", how can they at the same time "suffer!"

A survey by Dr. Keith Andrews of the Royal Hospital for Neurodisability (RHN) (BMJ 6/7/96) shed a very interesting light on the Sir Stephen Brown brand of human valuation. He found that of 40 people supposedly in "PVS" 43% were completely misdiagnosed. Of these 40 people 7 had apparently been in "PVS" for one year and 3 for over 4 years (remember that both the BMA and the Royal College of Physicians say people may ethically be starved to death after only one year in PVS (Sunday Telegraph 8/2/98).

One of these 'misdiagnosed' people was Geoff Wildsmith, a young musician who was diagnosed as being in PVS for two years, following an unexplained accident on a train. When he was eventually transferred to the RHN, he was fitted out with a buzzer system. This works by a nurse or a friend speaking out each letter of the alphabet in turn and the patient making his choice by tapping a buzzer once for yes, twice for no, using only the slightest twitch of a muscle. Geoff, who had up to then been assumed to be unable to see, hear, feel, talk or think then made his first buzzer message to the world.

The first letter he buzzed 'yes' to was 'G' which must have seemed an unlikely letter with which to start a sentence. He continued to buzz 'yes' to each of the letters of his name and finally his 'yes' buzzes revealed the extraordinary message - "Geoff is cool!".

The conversation buzzer continued slowly and painstakingly thus:

"Describe your experiences since the accident. How did you feel?"

Geoff answered: "Pretty awful, bored to tears."

He was asked. "What kept you going?"

Geoff replied: "Music. I was searching for my identity. I was strong inside. I prayed every night".

Finally and perhaps most significantly: "Do you want to live?"

Geoff answered by one very long buzz - a definitive "yes". (Guardian 19/11/96 Horizon 25/11/96)

Then there is Andrew Devine who, like Tony Bland, was injured in the Hillsborough Football stadium disaster. He showed signs of recovery after eight years in PVS, and it is now clear that he not only has a mind of his own still, but registers the same preferences (some might say prejudices depending on their own particular football allegiance) as before his injury. Using the same buzzer system as Geoff Wildsmith, the following conversation on football was held with Andrew Devine:

Q "Are Manchester United the best football team in the country?"

A Two taps - No.

Q "Are Liverpool the best team?"

A One long tap - very definitely yes!

Sadly Dr. Andrews said he believed his findings on recovery were not a reason to stop staring to death those regarded as "definitely" in PVS. He seems to be ignoring his own evidence, since both Geoff Wildsmith and Andrew Devine were diagnosed as "definitely" in PVS, Geoff for two years, and Andrew for eight years.

Equally alarmingly, Dr. Ronald Cranford, a US 'expert' said that the disabilities of the misdiagnosed "PVS" patients were "more horrifying" than PVS itself, and MORE reason to stop feeding than complete unconsciousness, since they had the 'ability to suffer'. So he wants to kill us when we do suffer - and .. when we don't! Prejudice seems too kind a word!

A Personal Experience

Perhaps the most compelling argument against euthanasia I can present, however, is myself. I have suffered a lot of pain in the past and still do now. Indeed there are many days when I spend much of my time working not only 'from home' but 'from bed' because any movement at all can set off severe pain and I need pain killers which are so strong they make me feel sick and I need yet more tablets to alleviate that.

Some years ago, however, about thirteen years ago - mental pain, due to several factors including being suddenly abandoned by my husband, compounded the physical pain to the extent that I began to think I no longer wanted to live. Over time, this became a settled wish and it lasted many years. During the first few years I attempted suicide many times. A few of the times were really 'cries for help', though in fact I believed myself

beyond all human help, and, as I was then an atheist, I had no understanding of help from any agency other than the human. Indeed I seriously believed the possibility that I had been 'born without a soul'.

At these times I would take moderate overdoses of pain killers or scratch my wrists badly enough to bleed quite a lot but not be dangerous. My mind was sick and confused and I simultaneously wanted to have more physical pain (to take my mind off the mental pain) and to sleep forever and ever and never hurt again. 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 I would use pins, needles, even paper clips and sharpened pencils to pick at the scars on my wrists.

Some of the attempts, however, were serious and I tried various methods large overdoses of various drugs and cutting my wrists badly. I was determined to succeed then, perhaps especially on one occasion that particularly sticks in my mind I had taken a large overdose of painkillers and cut my wrists badly (I had found an old penknife at the back of a drawer which had escaped the general removal of sharp objects). I then lay down in bed, cuddled my favourite bear and waiting 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 999. I was taken to hospital and treated against my will. I refused stomach pumping and treatment for my wrists, and remember thinking how stupid it was to ask for my consent "otherwise you will die" when that had been my specific intention, so they waited until I lost consciousness, then treated me anyway. If someone had asked me then if I truly wanted euthanasia, I know I would have said "yes" with no hesitation.

The Voluntary Euthanasia Society, of course, would say that under their proposed rules my request for euthanasia would have been denied because I was depressed. Quite apart from the fact that I think no one would look too closely at a person's mental state who qualified under all the supposedly 'strict safeguards' (which do not actually mention depression as a disqualifying factor), and that most requests for killing do in any case stem from some form of depression, I would certainly have been quite able enough to work the system. I was very sick, but I was not that big a fool.

Try now to imagine trans-locating my situation then to that of Holland now. I would have satisfied all their 'strict criteria' for voluntary euthanasia - incurable disability, severe, intractable pain; several doctors concurring my life expectancy would be significantly shortened; a settled wish to die and repeated requests to be killed as well as pain that could not be controlled. The fact that these were not the cause of my wish to die would never have been considered, (the Dutch rules specify only that these conditions must be present, not that they be the cause of the suicidal desire). I would have been killed, and thus denied the chance to rediscover my human value - a value which is not

compromised by the fact that even now I have severe pain which is not well controlled, the same incurable disability and occasionally, depression.

It would also have denied me the subsequent discovery of the existence of God, the joyful revelation that I not only had a soul but that it was immortal, and my eventual reception into the Catholic Church. I would have been denied all this solely because of the eugenic mentality, which states that people like me are 'right to want to die' and "better off dead."

The willingness to kill people like me who are capable of rediscovering (or in my case, perhaps, in many ways discovering for the first time) their human value, the acceptance of the philosophy that people in PVS may be killed, the devaluation of elderly people, the killing of young disabled children, despite protestations of 'compassionate motives' are really based on a deadly mix of emotion, economics and a negative view of human value and worth, where the infinite value of human beings is reduced to a relative value, depending on how closely the person approximates to arbitrary notions of 'normality'.

This robs disabled people of all their unique individuality, and makes them regarded as somehow less than fully human. If we are not allowed to be sometimes happy, sometimes unhappy; sometimes full of joy, sometimes at our wit's end, we are denied aspects of our true and full humanity. We have the duty to relieve suffering where possible, but it is in our response to those whose suffering seems to defy our best efforts at relief that we show the real depth of our compassion.

True compassion lies in reminding those who suffer that their suffering does not alter their infinite human value. Sham love, like that of people who say euthanasia is the 'loving response' to suffering lies in telling the suffering person "Yes, you are right to feel so hopeless - you do have no value" and colludes in the fallacy that there is such a thing as a life not worthy to be lived.

These ideas in truth only serve to add the inadequacies of the physically well to the suffering of the sick and disabled rather than counterbalancing the weakness of the vulnerable with the strength of will and determination of the healthy never to abandon their awareness of the infinite value of all human life.

Leo Tolstoy, the 19th Century Russian novelist summed up very well the way in which colluding with the despair of the sick and disabled actually increases rather than decreases their suffering with this little story: 'I sit on a man's back, choking him and making him carry me and yet assure myself and others that I am very sorry for him and wish to ease his lot by any means possible - except getting off his back' We should be sure that we never 'sit on the back' of those who suffer.

No killing of vulnerable people can ever be overlooked or dismissed as unimportant. Euthanasia is a very real threat to us all, but particularly to those who feel as desperate now as I once did. For their sake and mine (for I would not be here speaking to you now had euthanasia been legal then) I would ask you to remember that a really 'good death' is one which is in God's time, and not man's.

Far from achieving 'dignity' only in death, (pro euthanasia advocates are always keen to stress that they want 'death with dignity') what suffering people like me really want and need is support and encouragement to live with dignity - until we die in God's peace.

Alison Davis 3/98

Those wishing to quote at length from this talk should contact Alison Davis c/o S.P.U.C. at : the Society for the Protection of Unborn Children, Phyllis Bowman House, 5/6 Matthew Street, Westminster, London SW1P 2JT.

Cases of Withholding or Withdrawing Treatment

In Autumn 1998 the Medical Ethics Committee of the British Medical Association (BMA) produced a Consultation Paper on Withholding and withdrawing treatment and in February 1999 newspapers reported that doctors were to be given "the first guidelines" on this.

For very many years we, in the Handicap Division, have been aware that the deaths of disabled newborn babies, particularly those with Down's Syndrome or spina bifida as well as those born prematurely, may be brought about by doctors by withholding all food and fluids. This has all too often mischievously been called "letting nature take its course" or "allowing (them) to die".

In early January 1999 allegations of backdoor euthanasia came to light with investigations into the deaths of 50 hospital patients. 40 of the cases were at a hospital in Derby where nurses claimed demented patients were starved and dehydrated until they were so weak they died of infections. Three weeks later a further 6 cases came to light.

A bouquet for Dr. Gillian Craig, a retired consultant geriatrician who said,

"I would like to see this (withdrawing treatment) regime consigned to the dustbin of history. Attention to hydration is not merely an option, it should be a basic part of good medicine". The Times 6/1/99.

Having endorsed the killing of Tony Bland (who was PVS) in 1993, maintaining that assisted feeding was medical treatment which could be withdrawn, it seems that the BMA now wants to extend the categories of patients whose deaths doctors hasten.

BMA Guidelines

The Daily Telegraph (17/2/99) reported that the categories of patient being considered for having treatment withdrawn or withheld included

- people who have had severe strokes
- people with Alzheimer's Disease

- babies with multiple disabilities

It also noted that these were patients "whose medical condition is unlikely to cause their death within 3 months, but who need treatment including artificial feeding or antibiotics to keep them alive".

This means, of course, that doctors would be causing the deaths of patients who would not die with ordinary basic care, because of an assessment that their lives were "not worth living".

Disabled people are very much aware of the tendency of doctors to have a negative view of the value of disabled lives both before and after birth. We therefore urge BMA members to recall the basic truth that all their patients, however disabled they may be, have inherent infinite value, and should be helped to live, until their time comes to die naturally.

The Society for the Protection of Unborn Children set up the Handicap Division in the early eighties with five aims:

1. To promote equal rights for people with disabilities, including the most fundamental right of all - the right to life.
2. To monitor research and to produce factual information on measures designed to end the lives of disabled people including pre-natal screening tests which aim to detect and eliminate unborn disabled babies, the sedation and starvation to death of new-born disabled babies (often euphemistically referred to as "allowing to die") and euthanasia.
3. To promote greater understanding of the causes and effects of disabling conditions, and to promote research projects aimed at preventing the occurrence of disabling conditions.
4. To provide advice and information for women expecting a disabled baby.
5. To challenge the contemporary philosophy that disabled people are "better off dead".

Who are the "disabled"? The truth is we all are. We were helpless babies, we may become handicapped through disease or accident, we are, often, temporarily disabled through illness and we shall be increasingly dependent in old age. By attacking "the disabled unborn", the will to devote resources to the care of all those in need is undermined and every life is endangered.

