Submission

Assisted Dying for the Terminally Ill Bill

A submission to the House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill

by
The Maranatha Community
in association with the
Council for Health and Wholeness

August 2004

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1. Introduction

1.1 THIS DOCUMENT

This document has been prepared in response to the call for evidence by the House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill.

This submission has been addressed to Lord Mackay of Clashfern, Chairman of the Select Committee on the Assisted Dying for the Terminally Ill Bill, Committee Office, House of Lords, Westminster, London, SW1A 0PW; email assisteddyingbill@parliament.uk

1.2 THE MARANATHA COMMUNITY

The Maranatha Community is a Christian movement with many thousands of members throughout the country active in all the main churches. Its membership includes a substantial number of people involved in the health and caring professions and in a wide range of voluntary work. Since its formation 23 years ago, it has been deeply involved in work amongst children and young people, people with drug and alcohol problems, the elderly, the disabled and the disadvantaged. It has taken the initiative in a broad range of projects directly contributing to the health of the nation and it also has extensive international experience.

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The Maranatha Community Trust is a registered charity number 327627.
The Leader and co-founder of the Community is Mr. Dennis Wrigley.

1.3 THE COUNCIL FOR HEALTH AND WHOLENESS

The Council is a multi-disciplinary body embracing doctors drawn from a variety of specialist disciplines, nurses and various medical auxiliaries, counsellors, chaplains and others. It has close links with the healing ministry of the Christian church and is involved in a broad range of research projects.

The Council for Health and Wholeness is based in the offices of the Maranatha Community.
Its medical co-ordinators are Dr. Hans-Christian Raabe & Dr. Linda Stalley.

2. Summary

2.1 The Maranatha Community and the Council for Health and Wholeness welcome the opportunity to submit evidence to the Select Committee on the Assisted Dying for the Terminally Ill Bill. We believe that if this Bill were to become law, it would have a fundamental and deleterious effect upon our national life.

2.2 **The Maranatha Community and the Council for Health and Wholeness remain vigorously opposed to any attempt to legalise euthanasia or physician-assisted suicide**.

3. Definitions of terms used

3.1 **All definitions of euthanasia agree that euthanasia means shortening the patient's life, usually based on the belief that the patient would be better off dead**.
Euthanasia is the active, intentional termination of a patient's life by a doctor who thinks that death is of benefit to the patient.
Voluntary euthanasia is euthanasia at the request, or at least with the consent, of the patient.
Involuntary euthanasia is euthanasia carried out against the wishes of a competent person.
Non-voluntary euthanasia is euthanasia carried out on incompetent patients, such as babies or patients with dementia.
Active euthanasia is the intentional taking of a patient's life by a doctor who thinks that death is of benefit to the patient.
Passive euthanasia is the intentional termination of a patient's life by omission, for example by withdrawing treatment.
Physician-assisted suicide is where a doctor actively helps the patient to take his or her own life.

3.2 The European Association for Palliative Care in a recent statement emphasises that medicalised killing of a patient either without consent (non-voluntary euthanasia) or against their consent (involuntary euthanasia) should not be called euthanasia at all, since this constitutes murder. The Association also questions the distinction between 'active' and 'passive' euthanasia, stating that euthanasia is an active decision by definition. The term 'passive euthanasia' should be abandoned. The Association therefore recommends using the terms euthanasia and physician-assisted suicide only.[1]

3.3 **Intentionally hastening a person's death by omitting some medical interventions ('passive euthanasia') is entirely different from omitting disproportionate or futile treatment.** The act of withholding or withdrawing disproportionate treatments (because they are disproportionate or futile) is different from the act of omitting proportionate treatment with the 'active' intention to hasten death. In a confused discussion about euthanasia, some think that euthanasia may mean withdrawing life-prolonging treatment at the patient's request because it has become too burdensome for the patient. It is therefore

possible that some people surveyed by opinion polls who state that they are in favour of euthanasia may actually mean that they are in favour of being allowed to refuse burdensome treatment. However, it is perfectly possible to refuse medical treatment without the drastic step of legalising euthanasia.

4. Fundamental questions

4.1 The fundamental question is **can it ever be right to kill, even with the intention to relieve suffering?** The law of almost every country in the world is clear on this issue and prohibits euthanasia.

4.2 Human life has an intrinsic value. The Judaeo-Christian tradition holds that man is created in the image of God and therefore human life has an intrinsic dignity. This tradition underlies the moral and legal principle of the sanctity and inviolability of human life. It holds that one should never intentionally kill an innocent human being, apart from possibly in self-defence or in a 'just' war.

4.3 From a non-religious point of view and avoiding the term 'sanctity' this principle would be based on the term 'inviolability' of human life. The Hippocratic oath affirms this same principle, *not to prescribe a deadly drug and not to give advice causing death nor to procure an abortion*.[2] The Declaration of Geneva by the World Medical Association (1948) states: *'I will maintain the utmost respect for human life from its beginning'*. The same principle is also enshrined in the European Convention on Human Rights. Article 2 states: *'Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally*…' To legalise euthanasia would contradict the principles that have guided medicine for centuries.

4.4 Even if it were right to kill patients with the intention of relieving suffering, the second question immediately arises: **if euthanasia became legalised, would patients be killed through 'euthanasia' who did not request to die?** The experience of the Netherlands, where euthanasia has been legalised proves that this is indeed the case.

4.5 There is clear evidence from the Netherlands that voluntary euthanasia leads to involuntary and non-voluntary euthanasia, with at least one thousand patients including children being killed every year without their expressed consent and/or against their will. This constitutes murder. The Dutch experience shows that euthanasia, initially intended for certain groups such as patients with terminal diseases, will soon be performed on other groups of patients including the elderly, incapacitated patients, patients suffering with emotional distress, the disabled, and even children and newborn babies with disabilities.

4.6 Dr. Herbert Hendin, the President of the American Suicide Foundation states: ***'The Netherlands has moved from assisted suicide to euthanasia, from euthanasia for people who are terminally ill to euthanasia for those who are chronically ill, from euthanasia for physical illness to euthanasia for***

psychological distress, and from voluntary euthanasia to involuntary euthanasia *(called "termination of the patient without explicit request")* [3]

4.7 The Association for Palliative Medicine & the National Council for Hospice & Specialist Palliative Care Services state in a briefing on the earlier version of the Patient (Assisted Dying) Bill *"Euthanasia, once accepted, is uncontrollable for philosophical, logical and practical reasons rather than slippery slopes of moral laxity or idleness.* ***Patients will certainly die without and against their wishes if any such legislation is introduced.*** [4]

5. Euthanasia, patient autonomy and the 'right to die'

5.1 Advocates of euthanasia claim that euthanasia is about the 'right to die'. However, **euthanasia is not about the 'right to die', it is about giving doctors the 'right to kill'** their patients. This marks a fundamental and irreversible shift in the doctor-patient relationship. This is expressed in the statement by the British Medical Association on 'End of life decisions' (2000). Their spokesman said: *"I never want to have to wonder whether the physician coming into my hospital room is wearing the white coat of the healer ... or the black hood of the executioner."*

5.2 **If euthanasia became legalised, the decision whether to terminate or preserve a patient's life will rest with the medical profession.** Despite all the talk about 'patient autonomy' or 'patient choice' by proponents of euthanasia, ultimately, one or more doctors would have to make a value judgment as to whether a patient's quality of life is such as to preserve or terminate his or her life, or whether the patient would be better off dead. Despite all the claims by proponents of euthanasia, this would dramatically *increase* the power doctors have over their patients and severely decrease patient autonomy.

5.3 **To legalise euthanasia will lead to a fundamental change in culture similar to the change which occurred after abortion was legalised.**

5.4 Not only would legalising euthanasia cause a fundamental shift in the doctor-patient relationship, it would *"in the long run bring about profound changes in social attitudes towards death, illness, old age and the role of the medical profession. The Abortion Act has shown what happens. What ever the rights and wrongs concerning the present practice of abortion, there is no doubt about two consequences of the 1967 Abortion Act: a) The safeguards and assurances given when the Bill was passed have to a considerable extent being ignored. And b) Abortion has now become a live option for anybody who is pregnant…. Because abortion is now on the agenda, the climate of opinion in which such a pregnancy must be faced has radically altered."* (Archbishop Dr John Habgood; 1974)[5]

5.5 Similarly, **if euthanasia became legal, anyone with a medical condition – not just a terminal one – may consider euthanasia as a 'treatment option'**. Euthanasia then would become an acceptable 'treatment' option for conditions such as depression, stress, loneliness, fear of impending disease or fear of decline,

but also for disabled children or adults. Euthanasia would become part of the armamentarium of medical treatment alongside established medical treatments such as pain relief, antidepressant medication, radiotherapy and chemotherapy.

5.6 **As abortion is now an option for any woman who finds herself pregnant, euthanasia will become a 'treatment' option for anyone who is ill or considers him/herself to be ill.** Dr Karel Gunning, a Dutch General Practitioner states: *"Once you accept killing as a solution for a single problem, you will find tomorrow hundreds of problems for which killing can be seen as a solution."*

6. Euthanasia, palliative care and the wish to die

6.1 **The wish to die is often more an expression of depression, pain or the concern of being a burden rather than a genuine wish to die.** Research among terminally ill patients shows that the desire for death was strongest in those with severe pain and low family support but most significantly in those with severe depression. Nearly 60% of those patients who expressed a desire to die were depressed whereas depression was found in only 8% of patients without such a desire. The authors of this study conclude: *'The desire for death in terminally ill patients is closely associated with clinical depression – a potentially treatable condition – and can also decrease over time. Informed debate about euthanasia should recognize the importance of psychiatric considerations, as well as the inherent transience of many patients' expressed desire to die'*.[6] In another study of terminally ill patients those patients with substantial care needs were more likely to feel being an economic burden to others. This group was more likely to consider euthanasia or physician-assisted suicide..[7]

6.2 In Oregon, physician-assisted suicide (PAS) was legalised in 1997. With the increasing acceptance of PAS, the percentage of patients who died through PAS because they felt a burden to others (not necessarily the only reason, however) increased from 12% in 1998 to 26% in 1999 and to 63% in 2000 When Oregon legalised PAS, only a minority of patients requested PAS because they felt a burden to others. However, with the increasing acceptance of PAS, nearly two-thirds of those dying through PAS cite being a burden to family, friends or caregivers as one of the main reasons for requesting PAS. These figures cast very serious doubt over the assertion that the 'wish to die' is a truly autonomous decision. **There is the grave concern that patients feel pressurised into having euthanasia or PAS performed, because they consider themselves to be a burden to their family or society.**

6.3 Furthermore, nearly **one in two patients who initially requested physician-assisted suicide in Oregon changed their mind after initiation of treatment, such as pain control, prescription of antidepressant medication or a referral to a hospice**. However, among those patients, where no active symptom control was initiated, only 15% of those who initially requested physician-assisted suicide changed their mind. [8]

6.4 In a survey of terminally ill patients, a total of 60% supported euthanasia in a hypothetical situation, however only 10.6% reported seriously considering euthanasia or PAS for themselves. Factors associated with being less likely to request euthanasia were feeling appreciated, factors associated with being more likely to request euthanasia were depression, significant care needs and pain. At follow-up interviews **two to six months later, half of all terminally ill patients who had considered euthanasia or PAS for themselves changed their minds**, while an almost equal number began considering these interventions.[9] The waiting period of 14 days as specified in the Assisted Dying for the Terminally Ill Bill is therefore totally inadequate. ["Waiting period" in this Bill means the period of time between the date on which the patient first informed the physician of his wish to die and the date on which the patient is assisted to die.]

7. Euthanasia in Germany in the 1930s & 40s – What are the lessons?

7.1 No discussion on the issue of euthanasia is complete without considering the history of the euthanasia programme in Germany in the 1930s and 1940s, which was heavily influenced by the sinister eugenics movement. Between 1939 and 1945 German physicians participated in a euthanasia programme established to kill *'life not worthy of life'*. At the end of the war, an estimated 270,000 victims - disabled people or people with mental illnesses, the elderly and 'idiots' - were selected by doctors and terminated. This included approximately 8,000 infants with birth defects or congenital diseases such as Down's syndrome, and children with disabilities. The programme was expanded to include people with medical conditions such as epilepsy, polio, schizophrenia, paralysis and Huntington's disease. **The euthanasia programme demanded the co-operation of German doctors, who decided who was to be killed.**

7.2 The intellectual preparation for this was done through a 1920 publication by two German professors, a professor of Criminal Law, Karl Binding and a professor of Psychiatry, Alfred Hoche. Their book on euthanasia with the title *'Permitting the destruction of life not worthy of life*' was the first publication endorsing euthanasia by two highly respected academics.[10]

7.3 Proponents of euthanasia today argue that the experiences of Nazi Germany are irrelevant for the euthanasia debate. However, the ideology behind the euthanasia programme in the 1930s and 1940s in Germany was to deny the sanctity of life and to judge whether a life is worth living on a utilitarian principle, which is the same approach used by those favouring euthanasia today. Michael Franzblau, professor of medicine at the University of California who lost 25 relatives in the holocaust, has researched the Nazi ideology behind euthanasia. He states: ***'It is frightening to consider that many of the arguments made today by euthanasia advocates, echo almost precisely the arguments made by Binding and Hoche, and after them, Hitler and the Nazis as they implemented the euthanasia programme.'***[11]

8. Euthanasia in The Netherlands today – What are the lessons?

8.1 In an irony of history, the Dutch medical profession which mounted very strong and effective opposition to the German occupiers and resisting euthanasia are now actively participating in euthanasia.

8.2 In 1984 the Dutch Supreme Court ruled that doctors could lawfully perform euthanasia in certain circumstances. Subsequently, euthanasia was legalised and a number of conditions for euthanasia were laid down, for example that the request for euthanasia must come only from the patient, it must be entirely free and voluntary, the patient must experience intolerable – but not necessarily physical – suffering with no prospect of improvement, euthanasia must be the last resort and euthanasia must be performed by a physician who must have consulted with an independent colleague who has experience in this field.

8.3 Despite all these requirements, **1,000 Dutch patients are being killed every year without their consent**. In 1991, the first official report on the extent of euthanasia practised in the Netherlands was published. The report concluded that voluntary active euthanasia occurred in about 1.8% of all deaths or about 2,300 cases in 1990. There were almost 400 cases of physician-assisted suicide, some 0.3% of all deaths. Disturbingly, the report found that in a further 1,000 cases (0.8% of all deaths) physicians administered a drug with the explicit purpose of hastening the end of life **without an explicit request by the patient**.[12]

8.4 A second survey confirming the above findings was carried out in 1995-1996. Out of all the 135,500 deaths that occurred in the Netherlands in 1995 the survey estimates that still 0.7% or approximately 950 patients died through euthanasia without their explicit consent. Large doses of opioids that led to death were administered in nearly 20,000 patients which is equivalent to nearly 15% of all deaths.[13] In 2001, still **1000 deaths (0.7% of total) were due to patients killed against their wishes or without explicit consent.** 'Alleviation of symptoms' with possible life-shortening effects occurred in nearly one in five of all deaths, over 28,000 deaths in 2001.[14]

8.5 This data proves the fundamental shift which inevitably occurs in the doctor-patient relationship if euthanasia becomes legal. In Holland, over half of all Dutch doctors surveyed stated that they had performed euthanasia at some time. **23% of the doctors surveyed stated that they had ended a patient's life without his or her explicit request.**[15]

8.6 Currently, just over 50% of doctors in the Netherlands fulfilled their legal requirement and reported the case(s) of euthanasia they were involved in.[16] The low levels of reporting makes monitoring and prevention of abuse of euthanasia impossible. Furthermore, **two thirds of Dutch General Practitioners have certified a patient's death as resulting from natural causes when in fact it was**

euthanasia or assisted suicide.[17] The real numbers of euthanasia deaths in the Netherlands will be far higher than the reported cases

8.7 The profound change in the doctor-patient relationship through legalised euthanasia is furthermore shown by the fear of many Dutch patients that they may be killed even though they had not asked for euthanasia. In a Dutch survey of older people, nearly **60% of those polled were afraid that their lives would be terminated against their will.**[18] Half of the elderly living in their own homes and over 90% of those living in nursing homes were opposed to euthanasia. The Dutch Patients Association with a membership of 60,000 distributes a wallet card to protect members form being involuntarily euthanised. The card instructs that '*no treatment be administered with the intention to terminate life.'* Anecdotal evidence suggests that some Dutch patients prefer to be admitted to German hospitals where euthanasia is not legal for fear of being killed in a Dutch hospital against their will.[19]

9. Distressing medical 'side-effects' in physician-assisted suicide and euthanasia

9.1 While in active euthanasia the doctor terminates the patient's life, in physician assisted suicide (PAS) he assists the patient to take his own life. This may mean supplying a 'suicide pill' or developing a 'suicide machine' which injects the patient with a lethal substance. While some claim that PAS has to do with patient autonomy and his right to be in control – as opposed to active euthanasia, where the Doctor is in control – it is far from clear that there is a significant difference between the two. The supposed greater degree of patient autonomy is overstated, since the doctor would not agree to 'help' unless he thought that suicide would be in the patient's best interest. The practical difference may not be that much - what is the real difference between a patient taking a lethal medication into his mouth and swallowing it or the doctor placing the lethal medication into the patient's mouth and the patient swallowing it? In both cases, the patient has to swallow, therefore making the 'ultimate' decision to end his or her life.

9.2 In the Netherlands, no distinct moral difference is made between euthanasia and PAS. Dutch doctors are aware that they frequently need to intervene if PAS 'fails' and the patient needs to be killed by the doctor. Even though it is claimed that euthanasia is about having a 'good death', the reality is that frequently, unintended and very distressing complications occur when euthanasia and physician-assisted suicide (PAS) are carried out. **For example in 18% of cases where a patient attempted physician-assisted suicide the doctor had to intervene and kill the patient, therefore performing euthanasia.** The reasons for this were that the patient awoke from coma, or had difficulty taking all the oral medication, vomited after taking the first medication or fell asleep before taking all the medication. Furthermore, in nearly half of the cases which started as PAS the patient did not die quickly enough and the doctor had to terminate the patient. **While it was planned for the patient to die within half an hour after taking the lethal drugs, 19% of patients took 45 minutes to seven days to die.** There were less

problems observed in euthanasia as opposed to PAS but still 10% of patients took much longer to die, some up to seven days. In both euthanasia and physician-assisted suicide a small number of patients awoke from coma and had to be terminated.[20]

10. Conclusion

10.1 **The Assisted Dying for the Terminally Ill Bill essentially legalises euthanasia and physician-assisted suicide.**

10.2 Before considering legalising euthanasia, two questions need to be asked: **Is it ever right to kill, even with the intention to relieve suffering?** We are convinced that it is wrong to kill, even with the intention to relieve suffering. The law of almost every country on earth prohibits euthanasia.

10.3 **Even if it was right to kill with the intention to relieve suffering and euthanasia were legalised, could euthanasia be effectively controlled?** Would patients be killed through 'euthanasia' who did not request to die? The evidence from the Netherlands shows clearly that euthanasia, once legalised, cannot be effectively controlled. Patients are killed who did not ask for euthanasia. According to official Dutch data, 1,000 patients including children are killed every year without consent or without requesting euthanasia. This constitutes murder.

10.4 **Euthanasia will produce a fundamental and irreversible negative shift in the doctor-patient relationship.** No longer is it the doctor's sole duty to heal, it becomes his duty to kill his patients under certain circumstances. Euthanasia is not about the 'right to die', it is about giving doctors the 'right to kill' their patients. Evidence from the Netherlands shows that especially elderly patients are afraid of being killed without request. This seriously undermines the trust patients have in their doctors if the perception exists that doctors are allowed to kill their patients.

10.5 **Euthanasia will furthermore lead to a fundamentally negative change in attitude towards health, diseases and their treatment, and death.** Anyone with a medical condition – not just a terminal one – may consider euthanasia as a 'treatment option'. This shift is as fundamental as the shift that occurred after abortion was legalised. As abortion is now an option for any woman who finds herself pregnant, euthanasia will become a 'treatment' option for anyone who is ill or considers him/herself to be ill. Once killing is accepted as a 'solution' for a single problem, for example terminal illness, soon many other problems will be found for which killing can be seen as a 'solution'.

10.6 **The fundamentally negative change in attitude towards disease and treatment which inevitably occurs once euthanasia is legalised will have a devastating effect on the fabric of society.** Once euthanasia is legalised, many patients, especially those with serious illness, those who feel that, because of illness or disability, they are a burden to relatives or society or patients with conditions that

are expensive to treat will give in to the real or imagined pressure to have euthanasia and may be killed.

10.7 **The wish to die is often more an expression of depression, pain or the concern of being a burden rather than a genuine wish to die. Furthermore, the desire to die frequently changes over time.** In Oregon, nearly one in two patients who initially requested physician-assisted suicide changed their mind after initiation of treatment, such as pain control, prescription of antidepressant medication or a referral to a hospice. Even among terminally ill patients – the group for which this Bill is intended – half of patients who initially requested euthanasia changed their mind over the following two to six months. The 'waiting period' of 14 days stipulated in this Bill between request for euthanasia and euthanasia being performed is therefore totally inadequate.

10.8 **Even though it is claimed that euthanasia is about dying a 'good death', the reality is that very distressing complications occur when euthanasia and physician-assisted suicide (PAS) are carried out.** In nearly one in five cases where a patient attempted physician-assisted suicide the doctor had to intervene and kill the patient, therefore performing euthanasia. In nearly half of the cases which started as PAS the patient did not die quickly enough and the doctor had to terminate the patient, with some patients taking several days until they eventually died.

10.9 **For the above reasons, the Maranatha Community and The Council of Health and Wholeness remain vigorously opposed to legalising euthanasia and physician-assisted suicide.**

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