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

The Linacre Centre for Healthcare Ethics

Resume

Euthanasia is standardly defended by reference to one or both of two considerations: autonomy and welfare. Either consideration can lead to much more widespread euthanasia than defenders of its legalisation had originally envisaged. If euthanasia is about patient choice, why should the patient need to be terminally - or physically - ill to receive it? If euthanasia is about benefiting the patient, why should patients who cannot request it be deprived of this benefit? Thus we see in the Netherlands an extension of euthanasia to those who are mentally ill or 'tired of life', and also to significant numbers of patients who have not consented to it – including patients who could have consented but in fact have not. In this submission, we argue that respect for the patient's life is part of respect for the patient's human dignity, and that palliative care, not euthanasia, is the morally appropriate response to terminal suffering. The law should continue to uphold human dignity and equality by prohibiting homicide / assisted suicide for disabled and able-bodied alike. Suicidal people should not be confirmed in their own estimate of their lives' value; instead, they should be supported and protected, whatever their physical condition.

1. Introduction

The Linacre Centre for Healthcare Ethics¹ is a research institute under the trusteeship of the Catholic Trust for England and Wales. We publish material, run conferences and provide speakers on a range of bioethical issues, and also offer advice and information to individual health professionals and patients. We welcome the opportunity to contribute evidence to the Committee on the Assisted Dying for the Terminally Ill Bill, and would be pleased to respond to any questions the Committee may wish to raise on this evidence, or on related issues.

2. Respect for life

The Catholic Church holds - in common with other faiths - that human life is a gift from God, to be cherished and protected. In the Jewish and Christian understanding, human beings are created in the image and likeness of God, and God's loving care extends not only to the strong and well but to those who are suffering in body and mind. We do not have absolute dominion over our lives, but hold them in stewardship from God. The

¹ This submission has been prepared by Dr Helen Watt, the Director of the Centre, in consultation with Professor Luke Gormally, Senior Research Fellow at the Centre, Anthony McCarthy, the Centre's Research Fellow, Professor John Finnis of Oxford University and Professor John Keown of the Kennedy Institute of Ethics. Professor Gormally has also made a personal submission to the Committee.

appropriate response to human suffering is solidarity with, and care for, the sufferer; it is not deliberate killing of that person, with or without request. Respect for a human being cannot be divorced from a valuing of, and respect for, that person's presence in the world.

The Church teaches that the fundamental moral principles of Christianity are accessible to human reason, without reliance on revelation. Thus the secular belief in human equality, enshrined in the Universal Declaration of Human Rights of December 1948 (since recognized by the European Convention on the Protection of Human Rights and Fundamental Freedoms) squares well with the teaching of the Church on the basic equality of human beings. Human beings are 'equal' at a deeper level than their varying mental or physical condition might suggest: they are equal in their nature and basic dignity as human beings. An essential part of respect for human dignity is respect for the value of human existence: human bodily life. A valuing of each person's life, and a refusal to attack that life as 'worthless' or 'unwanted' by that person or others, is integral to a society in which all are valued and protected.

2.1 Suicide Act 1961

Thus the Suicide Act 1961 protects all members of society equally from assistance in suicide. The Act does not discriminate between disabled and non-disabled suicidal people: there is no suggestion that disabled people, unlike other suicidal people, have lives of doubtful worth which may therefore be curtailed. Many disabled people welcome the protection the Act provides from pressures to ask for 'help in dying' which they themselves might feel at times of pain or despair.

While decriminalizing suicide itself, out of concern for the survivor of a failed suicide attempt, the Act nonetheless treats suicide as contrary to the wider public policy of upholding human dignity and equality by excluding participation in intentional killing.² In its prohibition of assisting suicide, the Act is a central component in the network of laws protecting the vulnerable.

3. Defences of euthanasia

What are the ways in which voluntary euthanasia (and assisted suicide, which is not significantly different) are standardly defended? Euthanasia is normally defended by reference to one or both of two considerations: autonomy and welfare - the latter assumed to include the timely ending of a life thought 'worthless' or 'undignified.' These two considerations pull in different directions, and each in its own way can encourage a widespread practice of euthanasia, not limited to the cases permitted by the Assisted Dying for the Terminally Ill Bill. In the Bill itself, this tension between autonomy and welfare, and logical pressure to expand the grounds for euthanasia, are very much in evidence.

3.1 Autonomy

The stress on the patient's autonomy, and subjective assessment of the value of his or her life, can be seen in the way 'unbearable suffering' is given a purely subjective definition in the Bill: suffering, whether mental or physical, which the patient him or herself finds

² After the decriminalization of suicide itself by the Suicide Act, 'the policy of the law remained firmly adverse to suicide, as section 2 (1) [of the 1961 Act] makes clear'. The 1961 Act 'conferred no right on anyone [to commit or attempt to commit suicide]' (Lord Bingham in *Regina (Pretty) v. Director of Public Prosecutions* (2001), para. 35).

unacceptable. While the Bill requires the patient to be informed on alternative responses to his or her suffering, such as palliative care, a patient who rejects such alternatives, and states that the suffering is unbearable, may then be 'helped to die'. Although doctors conscientiously opposed to euthanasia will not be required to perform it, they will be required by the Bill to refer the patient to a more compliant colleague. Thus doctors will not be permitted to respect what they reasonably regard as the patient's best interests, but will be required to transfer the patient to someone they think will act in a way directly contrary to those interests. There is a negation here of the doctor's right to protect (or at least, not to threaten) the patient's interest in life, in favour of the patient's presumed right to secure an end to his or her existence. Even a patient who is suffering 'unbearably' can, the Act assumes, make a free choice to die which is not unduly influenced by depression or lack of knowledge of alternatives.

However, this emphasis on the patient's wish to die (rather than receive, for example, palliative care) is combined in the Bill with a requirement that the patient be terminally ill for euthanasia to be performed. It is difficult to see why this should be required: if the patient's suffering, whether mental or physical, is unacceptable to the patient, why is it relevant what the source of the suffering is? Why introduce this one 'objective' criterion of the patient's closeness to death, given that the suffering caused by a non-terminal illness, mental or physical, may be no more acceptable to a patient than that caused by a terminal illness?

3.2 Welfare

There is, in short, a wish to set some limits on patient autonomy and the presumed right to die.³ Most supporters of euthanasia would not defend it in cases where the patient was suffering from some purely temporary condition. This is because they see euthanasia as defensible not simply as something wished for by the patient, but as something which is in the patient's interests, objectively defined. Life, they think, has no value in some situations, though not in every case in which death might be sought; in particular, life has no value if the patient cannot look forward to any improvement in a serious and distressing illness.

However, once a 'welfare' view of euthanasia is adopted, there is once again a 'slippery slope' to other forms of euthanasia than those involving terminal illness, or indeed a voluntary request. The very existence of some human beings is seen as a bad or worthless thing, so that death is in such people's interests. But if this is true, why should euthanasia not be given to the chronically ill? And why should it not be given to children and the mentally incapacitated, who will also 'benefit' from it, but are unable to request it?

4. The Netherlands

The position of euthanasia advocates who stress both 'autonomy' and 'welfare' considerations is inherently unstable. There is not just a 'logical' but a 'practical' instability: either consideration can lead in practice to much more widespread euthanasia than

³ Few would argue that patient autonomy should be an overriding consideration in medicine generally. A doctor would not normally amputate a finger, or assist a patient in self-amputation, merely because this was requested.

was originally envisaged in official guidelines. Thus in the Netherlands we see both an extension of euthanasia to those who are mentally ill or ‘tired of life’⁴ and its extension to those who are unable to consent, such as infants and young children.⁵ Indeed, there is now official toleration of non-voluntary euthanasia, in that (for example) euthanasia of children is required to be reported. In 2001, 100 out of 1088 deaths of babies under one year of age involved the giving of drugs with the explicit purpose of ending life.⁶

Three major Government-ordered studies of euthanasia and other end-of-life decisions have been carried out in the Netherlands, where euthanasia was accommodated for many years by court decisions before being legalized by statute. These studies show a far

from reassuring picture with regard to observance of guidelines, including the requirement that the patient give consent.⁷ In the studies, the term ‘euthanasia’ is used in the official Dutch sense of ‘active voluntary euthanasia’; moreover, not all deliberate life-terminating acts - let alone deliberate life-terminating omissions - are classed as ‘euthanasia’, ‘assisted suicide’ or ‘life terminating acts without request’. To arrive at a more realistic, though still conservative, figure for euthanasia in the Netherlands, it is necessary to count all acts - and if possible, omissions⁸ - on the part of doctors which are chosen with the ‘explicit intention’ (or ‘explicit purpose’) of ending life. These figures are available for 1990 and 1995; however, the data for 2001 make it impossible to determine the exact level of (for example) non-voluntary active killing, since doctors who gave intentional overdoses of painkillers with the intention of hastening death were not asked, as in previous years, if the patient had consented.

⁴ With regard to grounds for euthanasia, 3% of doctors say that they have themselves assisted suicides of people ‘tired of life’ who did not have any serious somatic or psychiatric ailment (G. van der Wal, A. van der Heide, B.D. Onwuteaka-Philipsen & P.J. van der Maas, *Medische Besluitvorming aan het einde van het leven: De praktijk en de toetsing procedure [Medical Decisionmaking at the End of Life: The Practice and the Review and Verification Procedure]* (Utrecht, 2003), p.104, Table 10.2). 29% of doctors consider this an acceptable motive for assisted suicide (*Ibid*, p.107).

⁵ In Belgium, too, where euthanasia has recently been legalized, a member of the Belgian House of Representatives, Madame Avontroot, claims that many cases of non-voluntary euthanasia are performed, without even the family’s consent, and that the number of cases registered after a year (203) is far below the real number (see the electronic briefing of the Institut Européen de Bioéthique *Quality of Life – Spécial Belgique* January-June 2004, p.8). The president of a commission evaluating the law on euthanasia, Dr Distelmans, recently called for the law to be extended to minors and those with degenerative conditions such as Alzheimers who had made an advance request (*Ibid*, p.2).

⁶ Van der Wal, van der Heide *et al.*, p.121.

⁷ For an in-depth analysis of the first two studies, together with much other useful material, see J. Keown, *Euthanasia, Ethics and Public Policy* (Cambridge, 2002). For a summary statement of striking results of these studies which come into view when the terminological ambiguities are clarified, see J. Finnis, ‘Euthanasia, Morality, and the Law’, *Loyola University of Los Angeles Law Review* 1998, Vol.31, pp.1123-45 at pp.1125-8.

⁸ As John Keown comments on the 1995 study, ‘A note to the relevant questions [on withholding / withdrawing treatment with the explicit intention / purpose of hastening death] states that an intention to “hasten the end of life” could also be understood as an intention “not to prolong life”. This creates an unfortunate ambiguity ... An intention not to prolong life is not the same as an intention to end it. In many of these cases doctors may have intended to withhold / withdraw treatment not to end the patient’s life, but because the treatment was futile or too burdensome’ (*op cit.*, pp. 129-130).

4.1 Compliance with guidelines

When we read that 900 patients were deliberately killed without their request in 1995 (a figure which rose to 980 in 2001) we should remember that this figure, alarming as it is, does not include 1,537 cases where palliative drugs were given with the explicit, unrequested aim of hastening death.⁹ If we include this group of cases, it becomes clear that more than a third of those actively killed were killed non-voluntarily. Even excluding this group of cases of active non-voluntary euthanasia, one in five of those actively killed were killed without their request.¹⁰ If we turn to euthanasia by omission, there were as many as 18,000 such cases in 1995,¹¹ of which 14,200 – a substantial majority – were without the patient's request. It is worth noting that by no means all the patients killed without request, whether by act or by omission, were incompetent at the time.¹²

4.1.1 Reporting

It is often said that euthanasia will be better controlled where it can be freely

reported.¹³ In fact the Dutch experience shows widespread underreporting, in addition to widespread disregard of other guidelines. About half the cases of 'euthanasia' and 'assisted suicide' revealed by the 2001 survey went unreported, as did 99% of cases of termination of life without the patient's request, 100% of cases of intentional lethal overdose of painkillers (whether requested or unrequested), and a huge majority of cases where the patient killed was a child.¹⁴

This is in line with earlier research, which found that between 15% and 20% of doctors said they would not report their euthanasia cases under any circumstances, and that 20% of doctors' most recent unreported cases involved ending life without consent.¹⁵ Such cases, both the 1990 and 1995 studies revealed, were virtually never reported.¹⁶ Even

⁹ P.J. van der Maas *et al.*, 'Euthanasia, Physician-Assisted Suicide, and Other Medical Practices Involving the End of Life in the Netherlands', *New England Journal of Medicine* 1996, Vol. 355, p.1704.

¹⁰ Keown, *op.cit.*, p.128. The larger figure includes assisted suicide.

¹¹ See note 8.

¹² Indeed, of those killed without their request, between 25% and 40% (depending on the series studied) were capable of making a request, but did not do so. See Finnis, *op. cit.*, at p. 1126; Loes Pijnenborg *et al.*, 'Life-Terminating Acts Without Explicit Request', *Lancet* 1993, Vol. 341, pp.1165, 1197; The New York State Task Force on Life and the Law, *When Death is Sought: Assisted Suicide and Euthanasia in the Medical Context* (1994), p.134 n. 31; J. Keown, 'Euthanasia in the Netherlands: Sliding Down the Slippery Slope', in J. Keown (ed.), *Euthanasia Examined: Ethical, Clinical and Legal Perspectives* (Cambridge, 1995), at p. 292 n. 104.

¹³ A comparative study of six European countries (A.van der Heide *et al.*, 'End-of-life decision-making in six European countries: descriptive study', *Lancet* June 17, 2003, published online at

<http://image.thelancet.com/extras/03art3298web.pdf> shows a high rate of euthanasia in the Netherlands, and a relatively high, if not the highest, rate of non-voluntary life termination. (It is worth stressing that not all cases of active non-voluntary killing – much less non-voluntary killing by omission – will be included in these figures.)

¹⁴ R. Fenigsen, 'Dutch Euthanasia: The New Government Ordered Study', *Issues in Law and Medicine* 2004, Vol. 20, No. 1, p.77. It is striking to note that in 3% of these cases, the baby was euthanised without the consent or knowledge of the parents (Van der Wal, van der Heide *et al.*, Table 12.2) and that similarly in three cases older children were euthanised without the request of either the child or the parents (Table 13.2).

¹⁵ Van der Wal *et al.*, 'Evaluation of the Notification Procedure for Physician-Assisted Death in the Netherlands', *New England Journal of Medicine* 1996, Vol. 335, p.1708.

¹⁶ H.Hendin, 'The Dutch Experience', *Issues in Law and Medicine* 2002, Vol. 17, No. 3, p.230.

where euthanasia takes place ‘with consent’, there is a real possibility of pressure being brought to bear by doctors and / or relatives. It is startling to note that more than 50% of doctors surveyed thought it appropriate to suggest euthanasia to patients.¹⁷

As one researcher comments, ‘When, as the 1990 and 1995 studies document, 59% of Dutch physicians do not report their cases of assisted suicide and euthanasia, when more than 50% feel free to suggest euthanasia to their patients, and when 25% admit to ending patients’ lives without the patient’s consent, it is clear that terminally ill patients are not adequately protected.’¹⁸ Most striking of all, in both the 1995 study¹⁹ and the 2001 study,²⁰ the authors suggest that it is the *patient* who is responsible for avoiding termination of his life: if he does not wish euthanasia, he should say so clearly, orally and in writing, well in advance.

5. Palliative care

What then, should the terminally ill patient be offered in place of euthanasia, which the Dutch experience over many years has shown to be impossible to contain? Euthanasia in the Netherlands has been linked to poor palliative care, though such care is improving. Thankfully, the hospice movement in the U.K. is particularly strong; however, efforts

must certainly continue to extend high quality care to all who need it.²¹

We warmly endorse the holistic care provided, in particular, in the hospice setting: care responding to the patient’s physical, social, psychological and spiritual needs. It is worth remembering that drugs are not the sole response to the emotional distress a terminally ill person may experience. For this reason, we would question the wording of Clause 15 in the Assisted Dying for the Terminally Ill Bill, which gives the patient a right to ‘request and receive’ drugs which ‘may be necessary to keep him free as far as possible from pain and distress’. Without denying that drugs are sometimes needed to treat mental, as well as physical, suffering, it is the experience of those working in palliative care that patients can often be otherwise assisted to a point where they are fully reconciled with their situation, and able to use their last days to the full. Drugs are often not the best response to mental distress, and it would be wrong to require that such distress be removed ‘as far as possible’ by such drastic measures as making the patient unconscious throughout the dying period. It should be for the palliative care team to determine when there is no better response than sedation to mental suffering, though this option must be kept in mind.²²

¹⁷ P.J.van der Maas, J.J.M.van Delden and L. Pijnenborg, *Euthanasia and Other Medical Decisions Concerning the End of Life* (1992), pp.101-2.

¹⁸ Hendin, *op.cit.*, p.234.

¹⁹ G. van der Wal and P.J. van der Maas, ‘Euthanasie en andere medische beslissingen rond het levenseinde: De Praktijk en de Meldingsprocedure [Euthanasia and Other Medical Decisions Concerning the End of Life: The Practice and the Notification Procedure] (The Hague, 1996), p.237.

²⁰ Van der Wal, van der Heide *et al.*, p.201.

²¹ It is also important to safeguard the hospice movement itself from any euthanasiaist influences. To avoid the deliberate hastening of death - as opposed to the acceptance that death will occur - is central to the hospice ethos.

²² We are assuming here that there is no intention to hasten death. In fact, ‘terminal sedation’ is sometimes carried out with precisely this intention: the patient is sedated and feeding is withheld, not simply as futile or burdensome, but with the aim of ending life. Such euthanasia by omission is, in our view, morally comparable to active euthanasia.

We would emphasise the moral importance of intention in regard to palliative care (and indeed, human action generally). It is often permissible to accept a foreseen but unintended side-effect such as the shortening of life, or the patient's inability, due to sedation, to engage in social or spiritual activities. While it is normally the case that palliative drugs are more likely to extend than to shorten the patient's life, where the reverse is true, their use can still be justified, if the life-shortening side-effect is balanced by the intended effect of treating pain. The same can be said of the side-effect of shortening life as a result of stopping treatment which is burdensome to the patient. There is a significant difference between continuing to value the patient's life, while foreseeing that it will be shortened by giving or omitting treatment, and seeing life as having no value, and thus to be deliberately curtailed.

6. Conclusion

To conclude: a doctor's willingness to kill some patients – whether because this is their 'choice' and/or because the doctor thinks their lives have no value - undermines a commitment to the patient's true welfare which is basic to medicine. Voluntary euthanasia is not a 'private' choice: it very much affects (among other things) the character of doctors, and their treatment of other patients. Once legalized, euthanasia would become a 'quick fix' for disposing of 'difficult' patients in response to the demands they make on care. Medicine would be robbed of the incentive to find genuinely compassionate solutions to the difficulties presented by such patients. The kind of humane impulses which have sustained the development of hospice medicine and care would be undermined, because too many would

think euthanasia a cheaper and less personally demanding solution.²³ Doctors would be mistrusted by patients, who would die in an atmosphere of suspicion. Many patients would be killed without request, even if this remained illegal. The suicidal would be confirmed in their estimate of their lives' value, while the non-suicidal would be, at least, disheartened by the public view of lives such as theirs. For all these reasons, it is vitally important that society continue to value the lives of all its members, including those who, in pain or distress, do not see their own lives as worthwhile. Euthanasia betrays the suicidal by accepting their own view of their lives: suicidal people, whatever their physical condition, need protection and support.

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²³ See the Linacre Centre's 1993 *Submission to the Select Committee of the House of Lords on Medical Ethics*, 6.1.3 (5), published in L. Gormally (ed.), *Euthanasia, Clinical Practice and the Law* (London, 1994), pp. 154-5.