



CARE **NOT** KILLING

CONSIDERING PHYSICIAN- ASSISTED SUICIDE

An evaluation of Lord Joffe's
Assisted Dying for the Terminally Ill Bill

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'The debate on euthanasia has been in real need of a work of this quality. The combination of deep learning and the highest intellectual discipline make this an indispensable source for all. The reader will become factually enlightened and ethically enriched. And the debate should move to a level of serious enquiry which is essential if principle is to be protected against expediency.'

Lord Brennan

About the Author

Professor John Keown graduated in law from the University of Cambridge before taking a doctorate at the University of Oxford. After being called to the Bar he lectured in the law and ethics of medicine at the University of Leicester and then at the University of Cambridge,



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Introduction and Summary

Introduction

In 2003 Lord Joffe introduced the Patient (Assisted Dying) Bill which sought to permit physician-assisted suicide at the request of a competent adult who was suffering unbearably from a terminal or serious, incurable and progressive illness. The Bill was given a Second Reading but did not proceed. In 2004 Lord Joffe introduced another Bill, the *Assisted Dying for the Terminally Ill* Bill, which was limited to terminally ill patients and required a discussion with applicants of the option of palliative care. The Bill was given a Second Reading and referred to a Select Committee, chaired by Lord Mackay. The Committee produced its Report in April 2005 (ADTI Report) and the following November Lord Joffe introduced a revised *Assisted Dying for the Terminally Ill* Bill (ADTI Bill).¹ The ADTI Bill is likely to be debated against the backdrop of the ADTI Report. The evaluation of the ADTI Bill offered in Part II of this publication is therefore preceded in Part I by a consideration of the ADTI Report. As Lord Joffe's Bill is, moreover, typical of the sort of proposals currently being introduced in various jurisdictions to permit PAS, this publication should appeal to anyone interested in the PAS debate in general.

Summary

Lord Joffe's *Assisted Dying for the Terminally Ill Bill* (ADTI Bill) would, if enacted, allow doctors in certain circumstances to help patients kill themselves. It would permit doctors to give prescriptions for lethal drugs to legally competent patients who requested them and who were suffering 'unbearably' from a terminal illness likely to result in death within six months.

While one can understand the compassionate motives which surely lie behind the Bill, there are several reasons why it should be rejected. The Bill is open to objection in principle, not least as it would effect a radical break with the principle of the inviolability of life which has historically informed the criminal law and the ethics of the medical profession. But there are also

many practical objections to the Bill, several of which provide the focus of this publication.

The following points summarise some of the main practical objections to the Bill and some of the limitations of the House of Lords Select Committee Report (ADTI Report) which preceded it.

1. The Bill invites us to step onto a precipitous slope: from lethal prescriptions to lethal injections; from patients who are suffering 'unbearably' from terminal illness to those who are not; and from patients who can ask for accelerated death to those who cannot.

- (i) Lord Joffe has stated that the Bill is based on respect for personal choice. But if respect for choice is thought to justify lethal prescriptions for those suffering 'unbearably' from 'terminal illness', why does it not equally justify lethal *injections* for those who are neither suffering *unbearably* nor *terminally* ill? Lord Joffe has admitted that he would like the Bill to be 'of much wider application'. If it is enacted, it soon will be.
- (ii) As Lord Joffe has pointed out, there is another principle underlying the Bill: the principle that one ought to act humanely to alleviate suffering. But if this principle is thought to justify lethal prescriptions for those who are suffering and want them, why does it not equally justify lethal injections for those who are suffering *but are not capable of asking for them?* Once we accept the judgment that certain patients are better off dead, why deny them this benefit merely because they cannot ask for it?
- (iii) The experience of the Netherlands graphically illustrates the logic of the slippery slope and the speed of cultural change. In 1984 the Dutch courts allowed euthanasia on request. More recently, they have permitted euthanasia without request: the administration of lethal injections to babies with disabilities.

2. The Bill could not control the practice of physician-assisted suicide.

The Bill's proposed system of regulation, which essentially relies on self-reporting by doctors, is similar to that in the Netherlands. The Dutch experience has been one of widespread abuse perpetrated by doctors with virtual impunity. Official

¹ *Report of the Select Committee on the Assisted Dying for the Terminally Ill Bill*. HL Paper 86 - I. (An outline of Lord Joffe's earlier Bills can be found in para 4 of the Report.) The ADTI Bill is available online at <http://www.publications.parliament.uk/pa/ld200506/dbills/036/06036.i.html> and the ADTI Report (HL Paper 86-I) - together with its substantial volume of oral and written evidence (Paper 86-II) and with its slighter volume of selected individual submissions (Paper 86-III) - is available at <http://www.publications.parliament.uk/pa/ld/ldasdy.htm>. Hereafter, references to the Report's 'volume of evidence' relate to Paper 86-II.

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Dutch survey data reveal that since 1984 the law requiring a request by the patient has been ignored in many thousands of cases, and that the majority of cases of euthanasia have been illegally covered up by doctors.

Supporters of the Bill claim that in another jurisdiction which permits physician-assisted suicide, the US state of Oregon, there has been no abuse. Such claims are wide of the mark. The Oregon system of oversight is even weaker than that in the Netherlands. The Oregon law merely requires reports by doctors to be recorded, not investigated, and doctors are hardly likely to report their own failure to comply with the law. As Professor Alexander Capron (Director of the Department of Ethics at the World Health Organisation) has aptly commented, the safeguards in Oregon are 'largely illusory'. Absence of evidence of abuse is not evidence of absence of abuse. And, in any event, the few cases whose details have managed to pierce the veil of legal confidentiality are far from reassuring.

3. The 'safeguards' in the Bill are insufficient to ensure that individual patients who committed physician-assisted suicide would have made a free and informed decision unaffected by psychiatric disorder. The Royal College of Psychiatrists is, understandably, 'deeply worried' by the Bill.

- (i) Despite the fact that most patients seeking assisted suicide are suffering from depression, the two doctors the Bill would require the patient to consult need have no expertise whatever in psychiatry.
- (ii) The Bill would allow a patient to receive a lethal prescription even if the two doctors believed that the patient, though competent, was suffering from a psychiatric disorder causing impaired judgment.
- (iii) Even if the patient were competent when obtaining the drugs there is nothing in the Bill to ensure that when the patient takes the drugs, perhaps several months afterwards, the patient is still competent, let alone free from psychiatric disorder.
- (iv) The Bill merely requires the patient to meet with a palliative care doctor or nurse, not to have undergone a full assessment, let alone to have tried palliative care.

4. The Bill fails to adopt a number of key suggestions made by the ADTI Report, such as that

- (i) all applicants be referred for psychiatric assessment to ensure that they are not suffering from mental disorder causing impaired judgment.
- (ii) 'unbearable' suffering be replaced by 'unrelievable' suffering.
- (iii) more than the Bill's simple meeting with a palliative care doctor or nurse be required if patients are to be able to make fully informed choices.

5. The ADTI Report contains valuable insights (not least its questioning of pro-euthanasia claims about current public opinion and medical practice) but its summary of practice in the Netherlands and Oregon needs to be read with care.

The Select Committee visited the Netherlands and Oregon but interviewed relatively few critics of their laws. The Report also omits significant evidence (some of which was brought to the Committee's attention) such as the facts that:

- (i) in the Netherlands it is now taken to be the responsibility of patients to make it clear if they do *not* want euthanasia.
- (ii) Dutch law now approves of euthanasia for some patients who cannot request it.
- (iii) the Oregon Medical Association is opposed to the Oregon law.
- (iv) no US state has followed Oregon: many proposals to permit physician-assisted suicide have been rejected while several proposals to criminalise it have been passed.

A complete and balanced picture of the ongoing debate requires the ADTI Report to be read together with its accompanying two volumes of evidence and other evidence besides. Given that debate on the ADTI Bill is likely to be conducted against the backdrop of the ADTI Report, Part I of this publication considers the ADTI Report before analysing, in Part II, the ADTI Bill.

The views expressed in this publication are those of the author, who alone is responsible for its argument and accuracy.



I The ADTI Report

The Report states that it aims

‘to summarise, in as balanced a manner as possible, the evidence we have received on both the principles underlying the Bill and the practical implications which such legislation would have and to draw the attention of the House to a number of key issues arising from this which seem to us to be pertinent to the consideration of any future bill which might be brought forward on this subject.’ (para 268)²

As the Report of the previous Lords Select Committee on the subject (chaired by Lord Walton) showed,³ such Reports can make a valuable contribution to the debate about voluntary active euthanasia (VAE) and physician-assisted suicide (PAS). Producing a report on such a complex issue is an unenviable task involving as it typically does the sifting of a mountain of written and oral evidence, often conflicting. Moreover, not only may there be conflicts in the evidence submitted but there may be conflicts among Committee members about the proper interpretation and weight to be placed on that evidence. It is no secret that the Report which emerges may, in its search for the truth, be influenced by political compromise. It is therefore important to read not only volume I, the relatively brief Report produced by the Committee, but also volume II, the much more substantial volume of oral and written evidence heard by the Committee, as well as other evidence besides. This cautionary recommendation is not intended as a criticism of the Committee let alone its distinguished Chairman, Lord Mackay. It is simply a reminder that the conclusions and recommendations made in a Report will tend to reflect both the selection of witnesses and the selection of evidence tendered by those witnesses.

In the Lords debate on the ADTI Report in October 2005 both the Report and its Chairman attracted general praise.⁴ The Report can certainly boast a number of strengths. Chief among

them is its penetrating analysis of two of the major arguments for relaxation of the law: the allegedly common practice of VAE/PAS and allegedly widespread popular support for relaxation of the law.

The Committee helpfully commissioned a review of opinion surveys over the preceding ten to twenty years. It also solicited views from anyone who wished to write in and by the end of September 2004 had received over 14000 letters and emails and some 83000 cards or emails which formed part of organised petitions. (para 216) Significantly, the expressions of opinion it received were fairly evenly divided. Of those who sent individual letters or emails 50.6% supported the Bill and the remainder were opposed. The balance of opinion was broadly the same if the other communications were included. (para 231) As for the commissioned review of opinion surveys the Report concluded:

‘The research carried out up to this point into public and public health sector attitudes to the legalisation of euthanasia is limited in value and cannot be accepted at face value as an authentic account of opinion within the United Kingdom’. (para 232)

The Report continued:

‘This is particularly the case with regard to the attitudes of the general public, whose real views on euthanasia are clearly obscured by a lack of information on the subject and by the lack of opportunity to reflect in an informed way upon the implications of any change in the law for themselves and for society. The levels of agreement/disagreement with the concept of euthanasia which the numerous polls record are effectively built on what might be termed a “knee-jerk” reaction to the simple options provided by these polls and do not form a very useful guide to public opinion as support for legislative change’. (para 232)

Even in relation to opinion polls of health professionals, it added that ‘most research is superficial in coverage’ and that fresh, impartial research of a deliberative nature was required. (para 233)

² References to volume I (the Report) will take the form ‘para x’. References to volume II (the evidence) will take the form ‘II, p x’ when the citation refers to written evidence submitted by witnesses who testified and ‘II, p x, Q y’ when the citation refers to an oral question or answer to a question.

³ *Report of the Select Committee on Medical Ethics* HL Paper 21-I of 1993-4.

⁴ http://www.publications.parliament.uk/pa/ld199900/ldhansrd/pdvn/lds05/text/51010-04.htm#51010-04_head2. Last accessed 23 April 2006.

The Report's examination of the current incidence of illegal life-shortening by doctors is also illuminating. Referring to studies allegedly showing a significant incidence the Report shrewdly notes that 'it would be unsafe for us to assume that there has been no exaggeration or misunderstanding in any of these surveys', such as a confusion between intentional and merely foreseen life-shortening. (para 238) The Committee concluded that, bearing in mind a number of such factors, 'we would be surprised if covert euthanasia were being practised on anything like the scale which some of these surveys suggest'. (para 239) The Committee's scepticism has been borne out by a recent survey of end-of-life decision making in the UK, the most extensive carried out to date. Based on a postal questionnaire to 857 medical practitioners the survey found that the proportion of deaths in the UK from voluntary euthanasia was 0.16%; from physician assisted suicide, 0.00%; and from ending the patient's life without an explicit request, 0.33%. The author of the survey, Professor Clive Seale, observed that the proportion of deaths in the United Kingdom from voluntary euthanasia, non-voluntary euthanasia and physician-assisted suicide was 'extremely low' and that this finding suggested a culture of decision-making informed by a philosophy of palliative care. Moreover, Seale found that only 4.6% of doctors thought that the existing law had inhibited or interfered with their preferred management of patients, and that only 2.6% thought that relaxing the law would have facilitated management.⁵

There are, then, valuable insights to be found in the ADTI Report. Whether the Report succeeds in its aim of providing a balanced summary of relevant evidence is, however, less clear. This is essentially because, in gathering evidence about the experience VAE/PAS in the Netherlands and PAS in Oregon - a centrepiece of the Report - the Committee relied very largely on the testimony of those involved in the enactment or implementation of the respective laws. The Report's account of practice in those jurisdictions tends, therefore, to be too uncritical. As an analysis of volume II of the Report (the volume of oral and written evidence) indicates, the Committee received evidence from relatively few critics of the laws in those jurisdictions. Indeed, witnesses who objected to those laws were outnumbered more than four to one by those who did not.⁶ The Report inevitably suffers from a corresponding imbalance. This source of imbalance is, moreover, compounded by another. Some disturbing evidence which *was*

⁵ Clive Seale, 'National survey of end-of-life decisions made by UK medical practitioners' (2006) 20 *Palliative Medicine* 3, 6-8.

⁶ 23 to 4 in the Netherlands, 24 to 5 in Oregon. In respect of the Netherlands, evidence from the 23 who supported or at least did not oppose the law (which was taken over seven sessions) can be found at II, pp390-439 and II, pp451-487, and evidence from the 4 critics (taken during one session) is reproduced at II, pp 440-450. In respect of Oregon, evidence from the 24 who supported or at least did not oppose the law (which was taken over nine sessions) can be found at II, pp255-328 and II, pp344-361, and evidence from the 5 critics (taken during one session) can be found at II, pp329-343. (See also II, pp 593-602). One of the 24 (Dr Susan Tolle, who was interviewed by herself in one session) claimed to be neutral. (II, p277, Q673). For imbalance in vol III see n114, *infra*.

brought to the Committee's attention about the Netherlands and Oregon, often but not always by critics of overseas practice, is omitted from the Report.⁷

1 The Netherlands

The long experience of the Netherlands is central to the debate about whether VAE/PAS in the sort of 'hard cases' typically portrayed by campaigners could (even if those cases were morally unproblematic) be subjected to effective control. Whereas the law allowing PAS in Oregon has been in operation since only late 1997, Dutch law has permitted VAE and PAS for over twenty years. Again, the Dutch experience has generated a significantly greater wealth of literature and data, not least as a result of three comprehensive official surveys (published in 1991, 1996 and 2003⁸) involving anonymous interviews with physicians under a guarantee of immunity from prosecution. The Dutch have long claimed that their regulatory regime has controlled the practice of VAE/PAS and has forestalled any 'slippery slope'. Their claim is, however, undermined by their own data and by other evidence. The following points will consider the ADTI Report's summary of evidence on certain salient points about the Dutch experience and consider the cogency of that summary.

(i) The legalisation of VAE/PAS in 1984

It merits mention, as a preliminary matter, that the Report describes (para166) the Dutch Termination of Life on Request

⁷ Though the Report's imbalance in its representation of practice abroad is a focus of this publication, apparent lack of balance in at least one other respect should not be overlooked: the Report's identification of 'key' issues. All of the issues identified as 'key' by the Report (paras 268-269) concern the *scope* of legislation permitting VAE/PAS. The Report does not appear to consider as a 'key' issue the question whether such legislation is, irrespective of its scope, defensible *in principle*, even though this might well be thought key and was an issue on which the Committee properly solicited much evidence. It is also worth noting that chapter one claims that the Report avoids euphemistic terminology such as 'assisted dying'. (para 18) That phrase is, however, used five times in that chapter: see paras 1, 5, 7, 9, 10. Ms Vicky Robinson, a Nurse Consultant in Palliative Care, testified:

'assisted dying' is a misnomer: 'Midwives assist birth; palliative care nurses assist the dying with specialist palliative care: assistance is not killing. The use of the term "assisted dying" is offensive to those of us who are giving good care at the end of life and is a deception to sanitise the killing to make it more palatable to the public, the implication being that you can only die with dignity if you are killed'. (II, p151, Q354)

⁸ The three surveys are PJ van der Maas, JMM van Delden, L Pijnenborg, *Medische beslissingen rond het levenseinde. Het onderzoek voor de Commissie onderzoek medische praktijk inzake euthanasia* (The Hague, SDU Uitgeverij Plantijnstraat, 1991) ('first survey'); G van der Wal, PJ van der Maas, *Euthanasie en andere medische beslissingen rond het levenseinde. De praktijk en de meldingsprocedure* (The Hague, SDU Uitgevers, 1996) ('second survey'); G van der Wal, A van der Heide, BD Onwuteaka-Philipsen and PJ van der Maas, *Medische besluitvorming aan het einde van het leven: De praktijk en de toetsingsprocedure euthanasiae* (Utrecht, De Tijdstroom, 2003) ('third survey'). For an analysis of the first two surveys see John Keown, *Euthanasia, Ethics and Public Policy* (CUP, 2005) (Hereafter 'Keown') chs 9-12. For an analysis of the third see Richard Fenigsen, 'Dutch Euthanasia: the new government ordered survey' (2004) 20 *Issues in Law and Medicine* 73. (Hereafter 'Fenigsen'.)

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and Assisted Suicide (Review Procedures) Act 2002 as 'legalising' VAE/PAS and quotes a witness (from the Dutch Voluntary Euthanasia Society) that under the previous law it was 'a criminal act'. This is somewhat misleading. In 1984 the Dutch Supreme Court held that VAE/PAS were in certain circumstances *justified* by the defence of necessity. In other words, in those circumstances VAE/PAS were lawful: it was not that the doctor was merely excused punishment for what remained a criminal act. Consequently, the statute of 2002 was essentially a change of form rather than substance. As the Royal Dutch Medical Association told the Committee, the change was 'symbolic'. (II, p392) As the Report later notes (para167) the statute was 'effectively a codification of existing practices which had been built up on a basis of case law' (though even this paragraph cites a witness - another member of the Dutch Voluntary Euthanasia Society - who misleadingly refers to the statute as having 'legalised' VAE/PAS). During one of the hearings Lord Mackay accurately noted that the Dutch courts had recognised the defence of necessity as 'justifying' euthanasia. (II, p457, Q1550) It is unfortunate, therefore, that the Report should nevertheless contain references to 'legalisation' as having occurred in 2002 rather than 1984.

(ii) The incidence of VAE/PAS

The Report notes (para171) that approximately 16 million people live in the Netherlands of whom some 140000 die each year. Patients make some 9700 requests annually for VAE/PAS of which some 3500 result in VAE and 300 in PAS (around half of the remaining requests come to nothing because of the patients' demise⁹). The Report omits the fact that there has been a significant increase of one third since 1990, when there were only 2300 cases of VAE and 400 cases of PAS.¹⁰ The Report also omits to note that these totals reflect the narrow Dutch definition of 'euthanasia' as VAE, excluding, for example, the intentional termination of patients who are incompetent. The totals also ignore hundreds of cases in which doctors admitted taking active measures (the administration of opioids) with an 'explicit' (that is, primary) intent to hasten death at the patients' request (which the surveys oddly classify, instead of 'euthanasia', as the 'alleviation of pain and symptoms with the explicit intention of shortening life'.¹¹) The totals further ignore cases of 'terminal sedation' (the use of drugs to keep the patient in coma without artificial nutrition or hydration until death occurs) where the doctor's primary intent was to end life. Dutch researchers estimate that 'terminal sedation' accounts for 1400 deaths per year, in 17% of which the doctor's primary intent is to end life.¹² As one Dutch witness testified to the Committee:

'It is likely...that, recently,...so-called terminal sedation is replacing what before was called euthanasia. It is not reported because it is not called euthanasia and so, according to the law, there is not an obligation to report it'. (II, p445, Q1510)¹³

(iii) The slide from voluntary to non-voluntary active euthanasia

As we shall see, the Dutch experience confirms not only the *practical* difficulties of ensuring compliance with the guidelines but also illustrates what is often referred to as the *logical* slippery slope. The fact that many requests for VAE/PAS are refused in the Netherlands confirms that it is the *doctor* who decides whether requests are granted. As a Dutch witness explained to the Committee:

'It is...the exclusive competence of the doctor, and the doctor only, to decide whether or not he will terminate a patient's life on request'. (II, p433, Q1439)

And the doctor presumably grants requests in the light of whether, in the doctor's judgment, death would benefit the patient. But if the doctor can make this judgment in relation to a patient who can ask for euthanasia why cannot the doctor make the same judgment in relation to a patient who is not competent to ask for euthanasia? To put it another way, why should incompetent patients be denied this 'benefit' merely because they cannot request it? Is it not the duty of the doctor to act in the best interests of the patient even if the patient is incompetent? In short, the slippage from VAE to NVAE is likely to happen not only because of the *practical* difficulties of enforcing guidelines but because acceptance of the underlying justification for VAE, that certain patients are better off dead, *logically* involves acceptance of NVAE. This is illustrated by the fact that prominent philosophers who support VAE, like Professors John Harris and Jonathan Glover (both of whom appeared before the Select Committee: II, p12ff; p32ff), typically support NVAE.¹⁴

Despite the bold assurance of the Chief Executive of the Dutch Voluntary Euthanasia Society that:

'No doctor in The Netherlands - even if the whole family asks for it and everyone sees that there is hopeless and unbearable suffering - will ever terminate a life, because there is no request'. (II, p459, Q1566)

the three Dutch surveys have exposed the stark reality that doctors have ended the lives of thousands of patients without request. The ADTI Report notes (para178) the chilling statistic that every year in the Netherlands lethal injections are administered to around 1000 patients without, as the law requires, an explicit request by the patient. The Report quotes (para178) a witness from the Dutch Ministry of Health who

⁹ Fenigsen, 74 (citing third survey, 52-53).

¹⁰ First survey, 178-179 (see Keown, 94). Page references are to the English translation of the first survey, published as PJ van der Maas *et al*, *Euthanasia and Other Medical Decisions concerning the End of Life* (Elsevier, 1992).

¹¹ First survey, 72 (see Keown 96-98).

¹² Tony Sheldon, 'Dutch doctors choose sedation rather than euthanasia' (2004) 329 *British Medical Journal* (hereafter BMJ) 368.

¹³ The totals also exclude thousands of cases in which doctors admitted an 'explicit' intent to end life by withholding/withdrawing treatment. First survey, 90, table 8.15 (see Keown, 95).

¹⁴ See generally John Harris, *The Value of Life* (Routledge, 1985); Jonathan Glover, *Causing Death and Saving Lives* (Penguin, 1990).

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testified that about half of these patients are incompetent (as, for instance, in coma),

'25% are people who could have made a request but did not (so we are wondering about those), 15% are newborn babies, and 10% are other categories'.

The legal requirement of an explicit request is, therefore, ignored in 1000 cases. And in 250 of these cases (those about whom, some fifteen years after they were first uncovered, the Dutch are still 'wondering') the patient is either wholly or partly *competent*. Referring to the 1000 cases one of the lead Dutch researchers, Professor van der Wal, testified (para179):

'...we do not like these cases....We hoped that they would decrease in number, but it has not happened'.

He added:

'so far as we can see, there is no association between the development in jurisprudence and law and life-ending cases without a request'.

However, Dutch law has indeed developed to permit the ending of life without request. Dutch courts have held that just as the relief of suffering can justify the termination of patients who request euthanasia it can equally justify the termination of those who cannot. The Report fails to mention the fact (which was drawn to the Committee's attention: II, p411, Q1287) that Courts of Appeal in the Netherlands have held it lawful to administer lethal injections to disabled babies in certain circumstances.¹⁵ This aspect of Dutch euthanasia, among others, has drawn criticism from the UN Human Rights Committee.¹⁶ Notwithstanding the UN Committee's concern, in 2005 the NVAE of newborn babies was approved by the Dutch Paediatric Society and a protocol (referred to as the 'Groningen protocol' after the hospital where it was formulated) has been approved by the Dutch prosecution service to allow doctors to report such cases of NVAE without being prosecuted.¹⁷ In late 2005 the Dutch Government announced its proposal to establish a commission to lay down criteria for the NVAE of 'seriously suffering' newborns.¹⁸

¹⁵ Henk Jochemsen, 'Dutch Court Decisions on Nonvoluntary Euthanasia Critically Reviewed' (1998) 13(4) *Issues in Law & Medicine* 447 (see Keown, 119-120).

¹⁶ [www.unhcr.ch/tbs/doc.nsf/\(Symbol\)/CCPR.CO.72.NET.En?](http://www.unhcr.ch/tbs/doc.nsf/(Symbol)/CCPR.CO.72.NET.En?Opendocument) Opendocument, paras 5-6 (see Keown, 287.) Last accessed 23rd April 2006. The concern of the UN Committee was drawn to the ADTI Committee's attention (II, p393) but is not mentioned in the ADTI Report.

¹⁷ Tony Sheldon, 'Dutch doctors adopt guidelines on mercy killing of newborns' (2005) 331 *BMJ* 126. See also Eduard Verhagen and Pieter Sauer, 'The Groningen Protocol – Euthanasia in Severely Ill Newborns' (2005) 352 *New England Journal of Medicine* 959. A Select Committee member's observation that there had been talk about a protocol for neonatal euthanasia was met with a misleading response from the President of the Dutch Society of Nursing Home Physicians that the protocol concerned palliative care and the withdrawal of futile treatment. (II, pp484-485, Q1737-1741)

¹⁸ 'Dutch to set guidelines for euthanasia of babies' *MSNBC News* (29th September 2005) <http://www.msnbc.msn.com/id/9532252>. Last accessed 27 April 2006.

The slide from VAE to NVAE is, moreover, hardly surprising. This is not only because of the logical connection between VAE and NVAE but because, since VAE became lawful in 1984, leading figures in the Dutch political, medical and legal establishment have increasingly expressed approval of NVAE. For example, the first survey to disclose the 1000 cases (published in 1991) was commissioned by a government committee of inquiry (known as the R Emmelink committee, after its chairman) and this committee's report, far from condemning the cases of NVAE among the 1000 cases, condoned them. Describing the lethal injections administered in these cases as 'care for the dying' it concluded that ending life in these cases was justified because of the patient's 'unbearable suffering'.¹⁹ Similarly, the authors of the survey, Professor van der Maas *et al*, wrote:

'[Is] it not true that once one accepts [voluntary] euthanasia and assisted suicide, the principle of universalizability forces one to accept termination of life without explicit request, at least in some circumstances, as well? In our view the answer to this question must be affirmative'.²⁰

Finally, the ADTI Report omits a further disturbing piece of evidence relating to the annual 1000 cases. The evidence was drawn to the Select Committee's attention in oral testimony by Professor John Finnis, Professor of Law and Legal Philosophy at Oxford. Drawing on a paper by Dutch doctor Richard Fenigsen, which critically analyses the Dutch survey published in 2003, Professor Finnis testified that page 201 of this survey repeated the 'eye-opening assertion' made in the second survey (published in 1996) that:

'it is the patient who is now responsible in the Netherlands for avoiding termination of his life; if he does not wish to be killed by his doctor then he must state it clearly orally and in writing, well in advance'. (II, p554, Q1973)

Challenging this evidence, Lord Joffe stated (II, p563, Q2009):

'We took this back and referred it back to the people who prepared the report and they said they had never stated this and on page 201 I cannot find anything like this. So perhaps you could explore that...'

Professor Finnis (with the author's assistance) duly supplied the Committee with a copy of the relevant passages in the second and third surveys, together with a translation of those passages. Those passages confirm the accuracy of Finnis's testimony and refute the denial by the authors of the survey.

¹⁹ *Outlines [sic] Report Commission Inquiry into Medical Practice with Regard to Euthanasia* (Ministry of Justice, the Hague, no date). This is a summary of the Report published in English by the Ministry of Justice (see Keown, 104-105). The report of the R Emmelink Committee was not, unlike the survey it commissioned, translated into English: *Medische beslissingen rond het levenseinde. Rapport van de Commissie onderzoek medische praktijk inzake euthanasie* (1991).

²⁰ Johannes JM van Delden *et al*, 'The R Emmelink Study: Two Years Later' (1993) 23(6) *Hastings Center Report* 24, 25 (see Keown, 123).

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The passage referred to by Finnis on page 201 of the third survey reads:

'Due consideration should be given to the question how termination of life without explicit request can be prevented. It should be the responsibility of the patients, (their) next of kin, the doctors, the nurses, and the management, to clarify, well in advance, orally and in writing what are the wishes of the patient concerning the end of his life; for example, as a statement of will or as advance care planning.'²¹

Professor Finnis's revelation is indeed 'eye-opening' yet it is omitted from the ADTI Report.²²

Finally, the ADTI Report omits to note, first, the rarity of prosecutions of doctors for performing NVAE and, secondly, the leniency of punishments imposed when doctors have, even more rarely, been convicted of murder or assisted suicide. As Professor John Griffiths, a law professor in the Netherlands (and prominent supporter of VAE) has noted, from 1981 to 1998 there were only twenty final judgments leading to 9 convictions. Moreover, no punishment was imposed in 6 of these cases and the remaining 3 attracted only a suspended sentence. Griffiths has frankly commented that the Dutch regulatory system seems to be 'all bark and no bite'.²³ A graphic illustration of the leniency of the system is provided by a case which was tracked by the *British Medical Journal* from 2001. The case concerned the conviction of Dr Wilfred van Oijen for the murder of one of his patients, a comatose, dying 84 year old woman. Both her daughters had urged van Oijen to end her life but the patient herself had not requested euthanasia; indeed she had said she did not want to die. Nevertheless, van Oijen administered a lethal injection. He did not seek a second opinion and he reported the cause of death as natural. He was convicted of murder but his conviction attracted no punishment. The court stated he had made an 'error of judgment' and had acted 'honourably and according to his conscience' in what he considered the interests of his patient. The Royal Dutch Medical Association defended his actions as exhibiting 'complete integrity'. Van Oijen was also convicted of having reported the case as death by natural causes for which he received a suspended fine.²⁴ On appeal the court affirmed the convictions and for both offences

imposed a sentence of one week's imprisonment, suspended for two years. The Royal Dutch Medical Association then called for doctors who ended patients' lives without request to be allowed to report their actions and have them judged outside courts of law.²⁵ On further appeal, the Supreme Court affirmed van Oijen's convictions, noting that his patient was in a coma and was not suffering unbearably.²⁶ He continued to practise and his appearance before a medical disciplinary board resulted in only a warning.²⁷

(iv) The extension of 'unbearable suffering'

The ADTI Report also fails to note another aspect of the slope down which the Dutch have slid over the last twenty years. The guidelines have long required that in addition to making a request the patient be 'suffering unbearably' and that VAE/PAS be a 'last resort'. However, it is clear that both of these requirements have been stretched considerably. Evidence of how widely these criteria have been interpreted in the Netherlands was provided in 1989 by a leading and widely-respected Dutch practitioner of VAE. Asked whether he would rule out VAE for an old man who requested it because he felt a nuisance to his relatives who wanted him dead so they could enjoy his estate, the doctor replied:

'I...think in the end I wouldn't, because that kind of influence - these children wanting the money now - is the same kind of power from the past that...shaped us all.'²⁸

Again, 'unbearable suffering' has been held by the Dutch Supreme Court to justify PAS for a mother who was not terminally ill, or even physically ill, but who wanted PAS to put an end her grief over the death of her two sons.²⁹ Moreover, 'last resort' is often interpreted to include cases where palliative care could have alleviated the patient's suffering but where the offer of such care was simply declined by the patient.³⁰ There is also evidence to suggest that many Dutch patients since 1984 have not been offered the alternative of adequate palliative care. There has long been criticism of shortcomings in palliative care in the Netherlands. In its evidence to the Select Committee the Dutch Voluntary Euthanasia Society admitted:

'The practice of euthanasia developed in the Netherlands in the early 1970s. Palliative care as such did not really exist at this time...' (II, p454)

The Report notes (para183) that the approach to palliative care in the Netherlands is 'generalist' and that it is not recognised as a clinical speciality. One Dutch doctor (who is involved in the practice of VAE/PAS) is quoted in the Report (para184) as accepting that such care had been 'at a low level' but as

²¹ Third survey, 201 (lines 22-27) translation: Dr Richard Fenigsen. The Dutch original reads:

'Het verdient overweging om na te gaan op welke wijze levensbeëindigend handelen zonder uitdrukkelijk verzoek kan worden voorkomen. Hier ligt een verantwoordelijkheid voor patiënten, naasten, artsen, verpleging en management, om vroegtijdig, mondeling en schriftelijk, duidelijkheid te creëren over de wensen van de patiënt met betrekking tot diens levenseinde, bijvoorbeeld door middel van wilsverklaringen en advance care planning.'

²² Perhaps the Report's failure to explore the Dutch slide from VAE to NVAE is deliberate. One Dutch pro-euthanasia witness, when asked about NVAE, replied: 'We should leave this out, because you explicitly said that we would be talking about competent people'. (II, p416, Q1311)

²³ John Griffiths *et al*, *Euthanasia and Law in the Netherlands* (Amsterdam UP, 1998) 268.

²⁴ Tony Sheldon, 'Dutch GP found guilty of murder faces no penalty' (2001) *BMJ* 509.

²⁵ *Idem*, 'Court upholds murder verdict on doctor who ended woman's life' (2003) *BMJ* 1351.

²⁶ *Idem*, 'Two test cases in Holland clarify law on murder and palliative care' (2004) *BMJ* 1206.

²⁷ *Ibid*.

²⁸ Interview with Dr Herbert Cohen by Dr John Keown, 26 July 1989 (see Keown, 87).

²⁹ Hoge Raad, 21 June 1994, *Strafkamer*, no 96,972 (see Keown, 87).

³⁰ First survey, 45, table 5.7 (see Keown, 110).

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claiming that it had improved over the previous five years to a standard at least as high as in England. (II, p415, Q1305) He added (II, p416, Q1307): 'If you give proper care, you will see that the requests for euthanasia come down'. Whether palliative care in the Netherlands has improved as dramatically as this witness claimed is questionable. Another witness, the medical director of a hospice, testified (para183) that hospitals in general were 'totally devoid of input from palliative care specialists'. He added that the fact that palliative care is not regarded as a medical specialty explained why he had lost his job and was moving to the UK. (II, p446, Q1515) He noted that increased funding had come to an end, that hospices were under-resourced and that many people were losing their jobs. (II, p442, Q1491) Illustrating the use of VAE in place of palliative care, he referred to a case in which he had been consulted by a GP. The GP said that the problem was that the patient was refusing euthanasia:

I said, "What happened?". He said, "In the past, all these kinds of situations, when people were intractably vomiting, I solved by offering euthanasia. Now this patient does not want it, and I do not know what to do". That was really striking....This GP was not even aware of all the possibilities we have to control this kind of suffering.' (II, p449, Q1535)

Another witness commented that although the number of palliative care units had risen in the light of increased funding, the increased quantity did not mean improved quality. He testified (para185):

'many institutions which were providing nursing care in general were opening palliative care units, because they got more money for the patients....but these people are mostly just continuing what they were doing - in the sense that there is no real specialist understanding, knowledge and practice of palliative care...'

Further, the Report's presentation of the reasons patients request VAE/PAS is questionable. It quotes one witness who testified (para185) that

'84% of them have pain; 70% have extreme fatigue; 50% have gastrointestinal complaints and loss of weight; 70% have coughing, dyspnoea or suffocation; almost 70% feel extremely weak. Each of these symptoms or combination of symptoms may lead to a situation that, for these patients, is unbearable suffering and unacceptable, and that is basically the reason why they ask their GP to have their life ended'.

However, the three Dutch surveys carried out by Professor van der Maas *et al* have yielded vaguer reasons as to why those who received VAE/PAS sought accelerated death. Doctors surveyed replied that for 57% it was 'loss of dignity'; for 46% 'not dying in a dignified way'; for 33% 'dependence' and for 23% 'tiredness of life'. For only 46% was 'pain' a reason³¹

(and this, of course, raises questions about the quality of palliative care they were receiving, if any).

The Report also omits to note influential Dutch opinion in favour of accelerated death for those who are merely 'tired of life'. As early as 1991 a former Vice-President of the Dutch Supreme Court (Huibert Drion) argued that doctors should be able to provide elderly people over 75 who were living alone with the means of ending their lives.³² Similarly, in 2001 Mrs Els Borst, a former Minister of Health and leading figure in the development of Dutch euthanasia, stated that very old people who are simply 'tired of life' should be allowed to obtain a suicide pill.³³ And the Chair of the Medical Committee of the Dutch Society for Voluntary Euthanasia told the Select Committee that an 'end-of-life pill' for healthy old people, which could be obtained without consulting a doctor, was 'the ultimate goal' and 'one of the ideals of Dutch society in general at the moment'. (II, p418, Q1323)³⁴ Commenting on the third survey, Dr Fenigsen noted that it disclosed that 45% of the Dutch population and 29% of Dutch physicians think that older people who want to end their lives should have access to the means to do so.³⁵ Written evidence tendered to the Select Committee by the Royal Dutch Medical Association candidly observed:

'It is likely that, under the influence of "tired of life" cases, the emphasis of the debate will shift from physician-assisted death...to possibilities and options which limit or even rule out the role and influence of physicians'. (II, p393)³⁶

One of the few critics of Dutch euthanasia who testified commented generally on the slippery slope:

'Just look at what has been debated in the Netherlands from the summer until the present time [December 16th 2004]. First of all, it was again about life-terminating actions in newborn babies. You may have heard that in Groningen there is a protocol which is accepted by the legal authorities, and there is strong pressure from the medical profession - at least the KNMG [Royal Dutch Medical Association] - to accept it as a general rule. Second, euthanasia or assisted suicide for those who have the beginnings of dementia has been accepted by the authorities. A debate is starting whether this should not be done more generally. Just today, a KNMG committee has

³² Obituary: Huibert Drion, (2004) 328 *BMJ* 1204.

³³ <http://archives.cnn.com/2001/WORLD/europe/04/14/netherlands.suicide/> Last accessed 23rd April 2006 (see Keown, 110).

³⁴ Though the Dutch Voluntary Euthanasia Society was 'not actively campaigning for it at the moment', he said that its membership would very much support this goal. (II, 424, Q1355)

³⁵ Fenigsen, 76 (citing third survey, 108, table 10.6).

³⁶ 'Doctors can help patients who ask for help to die even though they may not be ill but "suffering through living," concludes a three year inquiry commissioned by the Royal Dutch Medical Association. The report argues that no reason can be given to exclude situations of such suffering from a doctor's area of competence.' Tony Sheldon, 'Dutch euthanasia law should apply to patients "suffering through living," report says' (2005) 330 *BMJ* 61.

³¹ First survey, 45, table 5.8 (see Keown, 108-109).

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published its report on an investigation into the possibility of accepting "tired of life" as an indication for euthanasia....[T]his committee is now saying that..."tired of life" could, in certain circumstances, be an indication for performing euthanasia. We therefore see that...the groups which are open to the possibility of getting euthanasia are definitely extending'. (II, p445, Q1510)³⁷

He also stated:

'social pressure is leading people to ask for euthanasia. Not asking for euthanasia has become an option...which you have to defend.' (II, pp441-442, Q1488)

About these developments and concerns the ADTI Report is silent.

(v) Underreporting

In its written evidence, the Royal Dutch Medical Association claimed that 'now and again' doctors ignored the guidelines but that 'evidence for abuse on a larger scale is lacking'. It added: 'it is not easy to neglect the core requirements and get away with it'. (II, pp395-396) The reality is somewhat different. As noted above (I (1)(iii)) doctors have intentionally ended the lives of thousands of patients without an explicit request. Moreover, as the ADTI Report notes (para180) in thousands of cases doctors have ignored the requirement to report cases of VAE/PAS to the local medical examiner. The three surveys disclosed non-reporting rates of 82% (in 1990) 59% (in 1995) and 46% (in 2001).³⁸ Moreover, since the passage of the euthanasia legislation in 2002, the number of reported cases has declined. As the *British Medical Journal* pointed out in 2004:

'The euthanasia law came into force in 2002 with the aim of improving reporting, but the total number of reported cases has continued to decline.'

It added:

'The latest figure - for 2003 - from the regional committees of lawyers, doctors, and ethicists that judge euthanasia and assisted suicide cases shows 1815 reports. This compares with 1882 for the previous year, 2054 for 2001, and 2123 in 2000.'³⁹

These statistics indicate, despite claims by the Dutch that legalisation has brought euthanasia 'into the open' and

subjected it to control, a considerable incidence of clandestine practice by Dutch doctors over the last twenty years.

The ADTI Report suggests that the number of cases of euthanasia may have been exaggerated, but its suggestion lacks foundation. It states (para181) that one of the three survey researchers who testified before the Committee

'believed that the wording of the research questionnaire...was insufficiently precise and that this had resulted in an inadvertent over-stating of the number of euthanasia cases'.

This account sits uneasily with the written record of her testimony. According to that record the witness testified that the relevant survey question asked doctors whether they had provided a drug with the explicit aim of hastening a patient's death and whether this had been done at the explicit request of the patient, and that, if the answer to both questions was affirmative, the survey classified the case as one of euthanasia. The witness stated:

'When the physician answers both questions "Yes", it is not that in all cases the physician himself defines the case as one of euthanasia'. (II, p472, Q1630)

However, the key issue is how euthanasia was classified by the *surveys* not by the respondent doctors. The surveys counted as euthanasia cases in which doctors replied that they had acted with the primary intent to hasten death at the patient's request.⁴⁰ Testimony that doctors may not always have shared the survey's classification of 'euthanasia' as intentional life-shortening on request is testimony neither that the survey classification was imprecise nor that the survey overstated the incidence of euthanasia. By analogy, if criminologists researching the incidence of 'rape' defined it as 'sexual intercourse with a woman without her consent', interviewed a sample of the population and arrived at a certain total, would it be a reason to regard that total as exaggerated if some of the married men who admitted having had intercourse with their wives without consent did not regard it as rape? Further clouding the issue the Report quotes (para181) another witness (from the Dutch Voluntary Euthanasia Society) who stated that if such alleged 'misunderstandings' were removed, the reporting rate might rise to 85%. The Report notes that this witness did not adduce any hard evidence to support this figure. Moreover, he inaccurately testified that cases in which doctors had 'any second thoughts' that the patient might die were classified as cases of euthanasia. (II, p420, Q1336) The surveys classed as euthanasia only those cases in which doctors said they had acted with the *explicit intent* to end life, not where they had acted partly with intent to end life, still less where they had merely foreseen the hastening of death.

³⁷ Another witness, a Dutch nursing home doctor with no evident objection to VAE, noted the gradual extension of VAE in the Netherlands:

'In the early 1980s, we started with the possibility of ending the life of terminally ill cancer patients....That has been slowly widened, little by little, step by step, until this point in time - where we have reached an area where we are out of the medical jurisdiction, out of the area where we can determine the criteria which are weighed, but it is in our domain because we are the ones who are asked to perform this action'. (II, p481, Q1712)

³⁸ Second survey, tables 11.1 and 11.2; Fenigsen, 77 (citing third survey, 192).

³⁹ Tony Sheldon, 'Dutch reporting of euthanasia falls - despite legal reporting requirements' (2004) 328 *BMJ* 1336.

⁴⁰ The surveys have distinguished life-shortening actions which were explicitly intended to shorten life from those where the shortening of life was only partly intended or was merely foreseen. First survey, 21 (Keown, 97).

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Significantly, the evidence tendered to the Committee by the lead researcher of the second and third surveys, Professor van der Wal, repeated without qualification the low reporting rates as found by the three surveys. (II, p469⁴¹) The ADTI Report gives no adequate reason to doubt these rates. Indeed, the reporting rate may in fact be *lower* than found by the surveys. This is because the surveys did not count as VAE many cases (mentioned above⁴²) in which doctors admitted that they had given a drug with the explicit aim of hastening a patient's death and at the patient's explicit request. For example, the first survey disclosed that in 1350 cases doctors administered increasing doses of palliative drugs with the explicit intent to hasten death and that the patient had explicitly requested that this be done in two thirds of these cases. As the authors of the survey commented: 'This situation is therefore rather similar to euthanasia'.⁴³ The survey did not, however, classify these cases as euthanasia. If they are included, the reporting rate falls correspondingly. Further, to the extent that doctors *intentionally* hasten death on request by way of 'terminal sedation' and do not report these as cases of euthanasia, the reporting rate again falls correspondingly.

Finally, even in relation to those cases which *are* reported there is no assurance that the doctor who performed VAE/PAS has complied with the law. The Select Committee heard from a member of one of the five regional assessment committees to which the reports are sent. The member testified (para175):

'we must be sure there has been no manipulation, no pressure or undue influence, and that the request is well-considered'.

But how *can* the review committee be sure when it relies essentially on information provided by the very doctor who ended the patient's life? As the same witness testified:

'...it is a paperwork exercise. On the basis of what is in the paper, we need to assess whether the requirements have been fulfilled'. (II, p435, Q1441)

And how extensive is the information supplied? The same witness stated:

'if you are ever going to develop a form, you should certainly not follow our form. The typography of it is limiting in the amount of information that you can provide'.

He added that the form 'certainly does not invite you to be extensive'. (II, p437, Q1454)

It is respectfully suggested that the ADTI Report's summary of evidence in relation to the Netherlands paints too favourable a picture. In view of the Report's heavy reliance on evidence tendered largely by leading defenders of Dutch euthanasia, this

is perhaps hardly surprising. The Committee may not, moreover, have been aware that the Dutch portrayal of their experience with euthanasia has not been free from 'spin'.⁴⁴

Rarely, a Dutch euthanasia advocate candidly concedes the lack of control. In 1990 the late Professor Henk Leenen, an architect of the Dutch euthanasia regime,⁴⁵ frankly acknowledged that there was 'an almost total lack of control on the administration of euthanasia' in his country.⁴⁶ In 1998, with no less candour, Professor John Griffiths admitted:

'To a large extent, the Dutch tend simply to ignore foreign criticism. The more or less "official" Dutch reaction, when there is one, amounts essentially to denial. Denial in the first place that there has been a major legal change in the Netherlands: euthanasia, it is insisted, remains "illegal". This position is essentially disingenuous....'

He continued:

'Denial, in the second place, that "non-voluntary euthanasia" is taking place.... Denial, most importantly, that there are problems of control. It is insisted that "carefully and precisely drafted rules" make abuse impossible. But even a passing acquaintance with the applicable rules... shows that they can hardly be described as watertight, and in any case a precise rule is quite a different matter from an effectively enforced one. It is well known in the Netherlands, and since the early 1990s this has become a subject of increasing concern, that the existing control system, depending as it does on self-reporting, cannot be regarded as adequate'.⁴⁷

Finally, much is made by euthanasia advocates of public support for VAE/PAS in the Netherlands and public trust in doctors. The Report quotes a witness (para190) that opinion polls in the Netherlands suggested that 92% approved of the fact that doctors would not be prosecuted if the criteria were met and that 91% thought euthanasia should be controlled. It is, however, doubtful if the Dutch public are aware of how frequently the criteria are not in fact met and of the laxity of the controls. There is little reason to believe that Dutch establishment 'spin' is intended solely for foreign consumption.

2 Oregon

The ADTI Report's outline of the law and practice of PAS in Oregon also needs to be read carefully alongside the oral and written evidence the Committee canvassed, and other evidence besides.

⁴¹ Another of the three researchers, Dr Onwuteaka-Philipsen, who co-authored a written submission with Professor van der Wal, was asked if the total of 3800 cases of VAE and PAS in 2001 should be 'quite a lot lower'. She replied merely: 'If anything, it might be a little bit of an overestimation'. (II, p471, Q1629)

⁴² See text at nn11-12, supra.

⁴³ First survey, 72 (see Keown, 98).

⁴⁴ Keown, 99-101; 139-141.

⁴⁵ Obituaries, Henk Leenen, (2003) 326 *BMJ*/226.

⁴⁶ HJJ Leenen, 'Legal Aspects of Euthanasia, Assistance to Suicide and Terminating the Medical Treatment of Incompetent Patients' (paper delivered at a closed conference on euthanasia at the Institute for Healthcare Ethics, Maastricht, 2-4 December 1990) (see Keown, 143).

⁴⁷ Griffiths *et al*, op cit n23, supra, 28-29 (see Keown, 142).

(i) The Death with Dignity Act

The Report's sketch (para 144) of the criteria for PAS set out in Oregon's Death with Dignity Act (DWDA) does not convey the laxity of the legislation. The reality is that the Act allows a 'terminally ill' patient who is psychiatrically disordered (though not so as to cause 'impaired judgment') to 'shop around' for any two doctors willing to certify that the Act's requirements have been met, even though neither doctor has seen the patient before or has any expertise in palliative care or psychiatry. It then allows the patient to make an oral and a written request for lethal medication (at para150 the Report mistakenly states that two written requests are required) which is witnessed by the patient's heir and the heir's best friend, and two weeks later to obtain lethal medication which is kept and taken months afterwards when the patient is suffering physically due to lack of palliative care and mentally due to psychiatric disorder which *is* causing impaired judgment. Professor Alexander Capron, a leading US expert on health law and currently Director of the Department of Ethics at the World Health Organisation, has observed that the safeguards in Oregon are 'largely illusory'.⁴⁸ And when Lord Mackay put it to a witness from the Oregon Department of Human Services (ODHS) - the body which is supposed to be notified by doctors who have written lethal prescriptions under the Act - that the Act prescribes 'minimal conditions', and that a good doctor might, but need not, do more than the law requires, the witness replied 'Very well said.' (II, p264, Q606)

The Report's account of the evidence from Oregon reflects the fact that the evidence was tendered largely by those who either campaigned for the law or who are involved in its implementation. Witnesses with objections to the legislation were, as in the Netherlands, outnumbered by more than four to one. The Report does not disclose, for the Committee may not have been aware, that even the Chief Executive of the Oregon Hospice Association who testified before the committee, Ann Jackson, has been described as a 'visible and vigorous promoter of assisted suicide'.⁴⁹

(ii) The incidence of PAS

The incidence of PAS since the DWDA came into operation in 1997 appears much lower than the incidence of VAE and PAS in the Netherlands. As one witness stated (II, p260, Q577) by the end of 2003, 265 lethal prescriptions had been written and 171 patients had taken them. (The Report mistakenly gives the figure as 117: para 150). The latest ODHS report, published in March 2006 and covering the year 2005, shows that the figures have risen to 390 and 246 respectively.⁵⁰ The apparently lower incidence in Oregon may be due to a number of factors, including the fact that the Oregon law allows only

⁴⁸ Alexander M Capron, 'Legalizing Physician-Aided Death' (1996) 5(1) *Cambridge Quarterly of Healthcare Ethics* 10.

⁴⁹ Personal communication from Mr Richard Doerflinger Deputy Director for Pro-Life Activities, US Conference of Catholic Bishops, 20th October 2005.

⁵⁰ Department of Human Services, *Eighth Annual Report on Oregon's Death with Dignity Act* (March 9th, 2006) <http://oregon.gov/DHS/ph/pas/docs/year8.pdf>, 4. Last accessed 23rd April 2006.

PAS not VAE. The Committee was told that Oregon provides good end-of-life care with high enrollment in hospice programmes (para154) and Ann Jackson from the Oregon Hospice Association testified (para155): 'very few Oregonians use the Death with Dignity Act. Hospice has been offered as the primary explanation for that'. On the other hand, a witness from the Oregon Nurses Association testified that staffing shortages had led to nurses reporting an inability to meet patients' pain needs effectively for probably four years. She continued:

'initially the percentage of nurses who said this was the case, either delayed or omitted pain management, was about 20 per cent. It is now up to 50 per cent even though the emphasis on pain management has remained the same or is slightly more vigorous'. (II, p358, Q1098)

She added that most of the small hospitals in Oregon did not have pain consultation teams at all. Indeed, the passage of the DWDA may have reflected not support for PAS as such but rather dissatisfaction with the availability of quality palliative care. One witness (who expressed no opposition to the law) commented that the referendum in favour of PAS was in some ways 'a vote of no confidence about some aspects of end of life care in Oregon'. (II, p281, Q689) She added:

'At the time the vote was taken I would say there was a definite dissatisfaction with some aspects of end of life care and some of those reflected dissatisfaction even 10 years earlier and some things had already begun to improve but people still remembered very graphically. We were held accountable for past and present sins at the time of the vote'. (II, p282, Q709)

(iii) Monitoring

Asked whether the number of reported cases could be relied upon as accurate a witness from the ODHS replied (para152) that the ODHS did get 'pretty good data' because physicians had a vested interest in complying with the law: if they complied with the legal requirements for PAS then they were protected by the law. However, Dutch doctors have the same 'vested interest' in reporting yet many of them do not. Should it be assumed that doctors in Oregon are more observant than doctors in the Netherlands? The same witness testified (para148) that 'there have not been any really egregious events'. It is difficult to see how she could claim to know. The ADTI Report states (para150) that the ODHS has the responsibility 'for checking that the basic requirements of the law are being observed' and refers to the Department's 'monitoring' of the process. But the 'checking' and 'monitoring' required by the law consists of passive recording rather than active investigation. As the Report explains (para150):

'The ODHS's role is simply to record what is happening, which includes compiling an annual report giving the number of lethal prescriptions issued and the number actually ingested'.

Even more accurately, the Department's role is to record what doctors who choose to report choose to say what is happening.

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If the doctors involved in issuing lethal prescriptions report that the legal criteria have been fulfilled (and the doctor's involvement may well end with the writing of the prescription) there is simply no reason for the ODHS to refer the case for possible investigation to the Oregon Board of Medical Examiners (OBME), the doctors' regulatory body. As a witness from the ODHS testified:

'...we are not a regulatory agency..., so if we see that there are any problems...our role is to report that to the Board of Medical Examiners...We do not call the police or take away their licence, we are not regulatory in that regard'. (II, p257, Q555)

The OBME has no more of a proactive investigatory role than the ODHS. As the representative of the OBME told the Committee:

'There may be instances in which there are problems, but if they are not brought to our attention there is no way for us to investigate them. In any area of medical practice, we do not go out and affirmatively go looking for trouble, so to speak'. (II, p323, Q897)

Similarly, the representative of the Oregon Medical Association (OMA) testified:

'The Board has very little jurisdiction over this Act because in essence, assuming the physician is following the law, they cannot take action against the physician based on his or her participation under this law'. (II, p346, Q1029)

He added:

'I am not aware of any evidence that things have either gone extraordinarily smoothly or extremely badly in any of the cases. As you are aware, the way the law is set up there is really no way to determine that unless there is some kind of disaster'. (II, p347, Q1035)

The Dutch have a regulatory system, however inadequate. It requires a doctor who has performed VAE/PAS to call in the local medical examiner who interviews the doctor and then files a report with the regional assessment committee which in turn considers whether the case appears to satisfy the law. In Oregon there is no equivalent procedure. The ODHS has an administrative rather than an investigatory role. Further, it operates, as one of its staff told the Committee, 'on a shoestring'. (II, p258, Q557) She added that the Department has neither the legal authority nor the resources to investigate cases. (II, p266, Q615)

The Report quotes Ann Jackson of the Oregon Hospice Association as testifying that if there were any abuses they would come to light because there were hospices all over Oregon 'and they have big mouths!' (para152). Jackson (who, it will be recalled, has been described as a prominent advocate of PAS⁵¹) added:

'We know that no-one has awakened, there have been no problems, and every outcome has been as it was supposed to have been...'. (II, p309, Q834)

These bold assertions should not be taken at face value. She neither substantiated her allegation that staff have 'big mouths' with evidence of breaches of confidentiality by staff, nor with evidence of complaints by staff about non-compliance with this (or any other) legislation, nor explained the incentive for any member of staff to expose a failure by a superior or a colleague to comply with the law, especially if they themselves were complicit in it. And, as she noted, only 2% of US hospice patients die in an inpatient facility (where there might be some opportunity for oversight) rather than at home. (II, p302, Q797) There is, moreover, no legal requirement on anyone, whether doctor or nurse, to be present when the patient takes the lethal substance. (Indeed, it appears that the prescribing doctor is present in only some 30% of cases: II, p348, Q1037). When anyone is present, it is often a member of Compassion in Dying, a pressure group which agitated for the DWDA and which is unlikely to be eager to report problems with its implementation. (The president of this organisation testified that it has 'participated in a consultative way with about three-quarters of the patients who have made a request' under the Act. (II, p310, Q837)) A critic testified:

'It is really not the doctors who are running this, it is Compassion in Dying volunteers who are in place and they do not like to say anything that is going to be embarrassing to them'. (II, p338, Q982)

Further, the doctors' notifications about the prescriptions they have written are confidential. And, as another critic testified:

'It is much easier to simply give a couple of prescriptions that are supposedly for sleep and say "Just keep these for a couple of months and then you will have enough to do yourself in", why would a doctor bother to report it?' (II, p341, Q1007)

How, therefore, Ann Jackson could claim to know that there have been 'no problems' such as patients availing themselves of the DWDA even though they were suffering from impaired judgment at the time of obtaining the prescription, or the time of taking it, is unclear. A defender of the DWDA testified that only 30% of patients received a psychological or psychiatric assessment and that that percentage was decreasing (II, p319, Q867). The latest ODHS report, for the year 2005, discloses that the figure has slumped to 5%.⁵² Refuting Jackson's testimony to the Committee the representative of the Oregon Nurses Association revealed that some of its members had admitted actually assisting patients to take the lethal substance (II, p353, Q1058), an evident abuse which appears, not surprisingly, to have gone undetected by the authorities. Another witness testified: 'It took six years before the Oregon Health Division's flawed tracking system even reported one

⁵¹ See text at n49, supra.

⁵² Op cit n50, supra, 12.

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case of vomiting'. (II, p334, Q954) As an eminent medical member of the Select Committee, Lord McColl, commented:

'If any surgeon or physician told me that he did 200 procedures without any complications I knew that he possibly needed counselling and had no insight. We come here and I am told there are no complications. There is something strange going on'. (II, p334, Q956)

In the Netherlands, a complication rate of almost 1 in 5 cases has been reported.⁵³ How tenable, then, are the claims that Oregon is problem-free?

Another witness, a psychiatrist from the Oregon Health and Science University who is studying the working of the DWDA (and who expressed no opposition to the Act) was asked by Lord Joffe whether after six or years of operation the safeguards appeared to be working adequately and the legislation was generally accepted. She replied: 'I think it needs more study...'. (II, p289, Q756)

The Oregon law is so lax that evidence of non-compliance is extremely unlikely to come to light. Though it might be going too far to say the law is designed *not* to detect abuse it is would certainly be reasonable to claim that it is not designed *to* detect abuse. And absence of evidence of abuse is not, of course, evidence of absence of abuse. Nor should it be forgotten that it was only some seven years after the courts in the Netherlands permitted VAE/PAS, and after a comprehensive government-sponsored survey, that the reality of the widespread abuses in the Netherlands came to light. Such comprehensive research, involving in-depth interviews with doctors granted immunity from prosecution, has yet to be carried out in Oregon. Further, the annual reports published by the ODHS into the operation of the Oregon law have contained frank admissions of the limitations of the regulatory framework. The first report admitted: 'we cannot detect or collect data on issues of noncompliance with any accuracy'.⁵⁴ The latest report acknowledges:

'our numbers are based on a reporting system for terminally ill patients who legally receive prescriptions for lethal medications, and do not include patients and physicians who may act outside the provisions of the DWDA'.⁵⁵

(iv) Critics

The handful of critics of the legislation who were interviewed by the Select Committee expressed grave concerns about the operation of the legislation. A general practitioner and Professor

at the Oregon Health Sciences University testified (para153) that 'every case that we know about, and it is close to a dozen cases now, has serious problems'. Dr Gregory Hamilton, a psychiatrist, related the case of one patient, Michael Freeland. Freeland was depressed, had a lifelong history of depression and previous suicide attempts, had been found incompetent by a judge and was left by his assisted suicide doctor with ninety barbiturate tablets with which to commit suicide. Freeland told Hamilton that when he rang the doctor to complain of pain, the doctor replied 'I will come and sit with you while you take your overdose'. Hamilton added that volunteers went to his house where Freeland

'was found alone in a deplorable condition in uncontrolled pain, delirious, and afraid to take his pain medicine. We had to physically give him his pain medicine. We did. The hospice did not do it. The assisted suicide doctors did not do it, volunteers did it'.

Dr Hamilton went on: 'This man was not in pain because his pain was not treatable, he was in pain because nobody bothered'. He added that the patient's palliative care doctor wondered whether he should be offered palliative care because he had drugs for assisted suicide at hand. 'This is', Hamilton commented, 'just one case among many'. (II, pp331-332, Q949)

Such cases in which the facts have, rarely, escaped the blanket of secrecy imposed by the Oregon law have tended to confirm doubts about the ability of the regulatory system to ensure that the legal criteria are satisfied, let alone that patients receive adequate evaluation, information and care. Testifying about a case which had come to the attention of the media, in which a man who could not swallow was 'assisted' in suicide by his brother-in-law, a witness from the ODHS stated:

'...the newspaper called us and said "What are you going to do?" and we said "Our job is to make sure that all the steps happened up to the point the prescription was written"'. (II, p259, Q566)

Two other cases whose details have emerged also raise disturbing questions. The first case was presented by Compassion in Dying as a model of how well the law works. It concerned 'Helen', a woman in her mid-eighties with metastatic breast cancer. Her own doctor had refused to assist her in suicide and a second doctor had also refused on the ground that Helen was depressed. Helen's husband phoned Compassion in Dying and was referred to a doctor willing to assist. In their critical analysis of this case palliative care expert Professor Kathleen Foley and psychiatrist Professor Herbert Hendin comment that even the limited details supplied by Compassion in Dying and by the prescribing physician give cause for concern. The physicians who evaluated Helen offered two contradictory sets of opinions about the appropriateness of her decision. As the decision-making process progressed it provided no mechanism for resolving the disagreement and the views of the two doctors who did not support the patient's decision – one who had known her for some time and another

⁵³ See text at n87, *infra*. The latest ODHS report states that three doctors reported complications. Two patients vomited some of the drugs. A third patient regained consciousness 65 hours after taking the drugs, did not obtain another prescription and died 14 days later from the underlying illness. *Op cit* n50, *supra*, 13-14.

⁵⁴ <http://egov.oregon.gov/DHS/ph/pas/docs/year1.pdf>, 9. Last accessed 23rd April 2006. The second report acknowledged: 'Underreporting and non-compliance is...difficult to assess because of possible repercussions for noncompliant physicians' who reported. <http://egov.oregon.gov/DHS/ph/pas/docs/year2.pdf>, 12. Last accessed 23rd April 2006.

⁵⁵ *Op cit* n50, *supra*, 15.

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who considered that she was depressed – were essentially ignored. The prescribing doctor admitted he did not discuss Helen's case with her regular doctor and had only very cursory contact with the second doctor who thought Helen was depressed. The prescribing doctor also revealed that although he liked Helen and found the thought of her dying so soon 'almost too much to bear' he found even worse 'the thought of disappointing this family. If I backed out, they'd feel about me the way they felt about her previous doctor, that I had strung them along...'.⁵⁶

A second case analysed by Foley and Hendin concerned Kate Cheney, an 85 year-old widow terminally ill with stomach cancer. Kate, accompanied by her daughter Erika, who had moved from Arizona to care for her, went to request assisted suicide from her physician at her Health Maintenance Organisation, Kaiser Permanente. Erika described this doctor as 'dismissive' and obtained a referral to another doctor with Kaiser. This doctor arranged for Kate to be psychiatrically examined. The psychiatrist concluded that Kate did not seem to be explicitly pushing for assisted suicide, that she lacked the high level of capacity to weigh options about it, and noted that although Kate seemed to accept this assessment her daughter became very angry. Kaiser then suggested another assessment from an outside consultant. This consultant concluded that Kate was able to decide although her choices might have been influenced by her family and that Erika might have been 'somewhat coercive'. Kate received the lethal drugs and later took them. Foley and Hendin observe:

'Caregiver burden leading to depression in the caregiver has now been identified as a serious issue, particularly for women like Erika who are asked to shoulder the work and responsibility of providing twenty-four hour care to a parent. This particular case raises the question of what real meaning or value is Oregon's prohibition of coercion if it can be circumvented so easily'.⁵⁷

Another expert on the Oregon law, Dr Neil Gorsuch, comments that such cases

'encapsulate and illustrate some of the many difficult questions about Oregon's assisted suicide regime alluded to by the [Oregon] data...: what is the role of depression, as opposed to terminal illness, actually playing in patient decisions to die in Oregon? Are alternative options, including treatment for depression, being fully presented (or presented at all)? Are the doctors prescribing death even knowledgeable about the alternatives that exist? To what extent are family members unduly influencing patient choices and physician evaluations? What would have happened if family members in each case had argued *against* the request to die and offered care? Should patients be allowed to "shop" around for physicians and

psychologists who will find them competent? Do psychologists and physicians have an obligation to do more than a cursory examination? Should they consult the patient's primary care providers and other doctors and psychologists who may have refused prior requests for lethal medication by the patient? Would Cheney's HMO have offered to pay for a second opinion if the first psychologist had found Cheney competent? Do HMOs have a conflict of interest – given that assisted suicide is unquestionably cheaper than continuing care – that may provide an incentive for them to encourage patients to seek death?'⁵⁸

Such questions await answers by supporters of the Oregon law. Professor Hendin *et al* have observed that under the Act

'substandard medical practice is encouraged, physicians are protected from the consequences, and patients are left unprotected while believing they have acquired a new right'.⁵⁹

In a 1999 analysis of the first official report from Oregon, Foley and Hendin concluded that the report was misleadingly reassuring and that the monitoring process was essentially a case of 'Don't Ask, Don't Tell'.⁶⁰ They commented:

'The Oregon law is significantly flawed. Oregon doctors who assist in a suicide are not required to report how they made their diagnosis or prognosis, nor required to be knowledgeable about palliative care, and not obliged to consult a physician who is and who may know how to relieve their patient's suffering'.⁶¹

Nor, they added, despite the fact that two-thirds of all suicides and two-thirds of those requesting physician-assisted suicide are suffering from depression,⁶² does the law require consultation with a psychiatrist to see if relievable depression or anxiety is at the source of the patient's requests to die. They pointed out that studies have shown that physicians are not reliably able to diagnose depression, let alone whether depression is causing 'impaired judgment', and that in one study only 6% of Oregon psychiatrists were confident that in the absence of a long-term relationship with a patient they could satisfactorily determine in a single visit whether that

⁵⁶ Kathleen Foley and Herbert Hendin, 'The Oregon Experiment' in Kathleen Foley and Herbert Hendin (eds), *The Case Against Assisted Suicide: For the Right to End-of-Life Care* (Johns Hopkins UP, 2002) 144, 146-150.

⁵⁷ *Ibid*, 156-157.

⁵⁸ Neil M Gorsuch, 'The Legalization of Assisted Suicide and the Law of Unintended Consequences: A Review of the Dutch and Oregon Experiments and Leading Utilitarian Arguments for Legal Change' (2004) 5 *Wisconsin Law Review* 1347, 1383.

⁵⁹ Herbert Hendin *et al*, 'Physician-Assisted Suicide: Reflections on Oregon's First Case' (1998) 14(3) *Issues in Law & Medicine* 243 (see Keown, 175-176).

⁶⁰ Kathleen Foley and Herbert Hendin, 'The Oregon Report: Don't Ask, Don't Tell' (1999) 29(3) *Hastings Center Report* 37.

⁶¹ (2000) 30(1) *Hastings Center Report, Letters*, 4, 5.

⁶² *Op cit* n60, *supra*, 39. A recent study of 138 terminally-ill cancer patients in the Netherlands found that depressed patients were more than four times more likely to request euthanasia than patients who were not suffering from depression. Marije L van der Lee *et al*, 'Euthanasia and Depression: A Prospective Cohort Study Among Terminally Ill Cancer Patients' (2005) 23 *Journal of Clinical Oncology* 6607.

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patient was competent to commit suicide.⁶³ Moreover, the monitoring process was flawed:

'Physicians participating in assisted suicide are not asked to provide [the ODHS] with significant medical information about their patients. They are merely asked to check off a list on an [ODHS] form indicating that such statutory requirements as a written request for a lethal dose of medication, a fifteen-day waiting period, and consultation with another physician have been met....The form does not even inquire as to the patient's reasons for requesting assisted suicide. The data do not make it possible to know what transpired in any particular case'.⁶⁴

They added that the methodology developed by the ODHS for studying the operation of the law was also inadequate. The ODHS report concluded that patients who were assisted in suicide were receiving adequate end-of-life care and made much of the fact that a high percentage had advance directives and were enrolled in hospice programmes. But, Foley and Hendin commented: 'neither advance directives nor enrollment in a hospice program, any more than admission to a hospital, are proof of adequate care'.⁶⁵ They continued:

'Neither hospice nurses nor social workers who may have the most knowledge of the patients were interviewed. Nor were physicians interviewed who initially saw the patients but did not agree to assist in the suicide. Nor were family members interviewed'.⁶⁶

They observed:

'we know nothing about the physical, psychological, social, economic, or existential needs of the Oregon patients requesting assisted suicide. We know little of the capabilities of the physicians who responded to these requests. And we know nothing of the context in which these patients live and are cared for'.⁶⁷

No less disturbing, they claimed, was that, as in the Netherlands, those administering the law had become its advocates.⁶⁸

Addressing the typical character traits of those who have availed themselves of the DWDA, the ADTI Report notes (para163) that they are 'persons who have always been in control of their lives and ordered their lives and want control'. This motivation is, of course, quite different from the avoidance of 'unbearable suffering' on which the argument for PAS typically rests. Moreover, the Report does not mention the main reasons that patients have opted for PAS in Oregon. Those reasons are not unbearable pain or suffering (which is not in any event a requirement for PAS under the law). As Ann Jackson of the Oregon Hospice Association testified about the

DWDA: 'no-one has used it because they were in pain'. (II, p301, Q793) The latest official report from the ODHS confirms that

'The most frequently reported concerns included a decreasing ability to participate in activities that make life enjoyable (89%), loss of dignity (89%), and losing autonomy (79%)'.⁶⁹

The report also notes an increasing motivation: that of becoming a burden to family friends or caregivers. This concern influenced 42% of patients in 2005 (up from 36% between 1998 and 2004).⁷⁰

Similarly, Ann Jackson testified as to the main reasons hospice patients had resorted to the DWDA to end their lives:

'Controlling the time of death was overwhelmingly identified as the primary reason....Being ready to die was #2. Dying at home instead of in a hospital was identified at #3. Existence being pointless at #4, losing independence #5, and poor quality of life at #6. Fear of pain was #8'. (II, p297)

She added:

'They are not using assisted suicide because they need it for the usual medical kinds of reasons, they are using it because they tend to be people who have always controlled the circumstances of their lives and they prefer to control their death in the same way'. (II, p303, Q806)

An illustration of the extent to which a desire to control the circumstances of death lies behind use of the legislation was given by one witness who assists patients to use it. She said:

'Some time ago a patient kept asking his wife "Is it 15 days yet? Is it 15 days yet?" and her sadness at watching him trying to hold on long enough for the 15 days and then the 48 hour waiting period, she still grieves that she could not help her husband to achieve his goal before that experience'. (II, p290, Q762)⁷¹

Psychiatrist Dr Hamilton testified to the Committee:

'All of the cases are basically for psychological and social reasons...and there is not one documented case of a patient dying from assisted suicide because of uncontrollable pain'. (II, p332, Q949)

He also commented: '99.9 per cent of people in Oregon do not die with assisted suicide...and that is because nobody needs it. The other 0.1 per cent could die without it too'. (II, p333, Q954) In a paper on the first report issued by the Oregon

⁶³ Op cit n60, supra, 39-40.

⁶⁴ Ibid, 37.

⁶⁵ Op cit n61, supra, 5.

⁶⁶ Ibid.

⁶⁷ Op cit n60, supra, 37.

⁶⁸ Ibid, 42.

⁶⁹ Op cit n50, supra, 14.

⁷⁰ Ibid, 23, Table 4. See also the ADTI Report, II, p358, Q1101.

⁷¹ Lord McColl asked why, if those who availed themselves of the law were 'type A' controlling personalities they did not simply commit suicide without assistance, to which the psychiatrist witness answered that suicide was illegal in Oregon. (II, p292, Q780) The witness later corrected this answer noting that suicide is not illegal in Oregon but that the DWDA allows families to collect life insurance benefits they might otherwise be denied. (II, p292, Q780 n1)

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authorities Dr Hamilton echoed the criticisms levelled by Professors Hendin and Foley. He claimed that a 'culture of silence' had developed and that those assigned to monitor PAS had become 'its apologists, if not its advocates'.⁷² He added:

'Implementation of assisted suicide is being treated as a potential political embarrassment to be justified, rather than as a health concern to be frankly reported. Under such political pressure, the authors of the health division report made exaggerated claims of safety and withheld vital information'.⁷³

He cited as an example the ODHS report's claim that economic factors had not influenced patients because a majority had some kind of medical insurance. Hamilton pointed out that the report ignored the fact that Oregon's rationed health plan denied payment for 173 services while fully funding assisted suicide for the poor and that within weeks of the Oregon law being implemented the state placed restrictions on funding some of the most widely used and needed psychiatric medicines for the poor.⁷⁴ He added that although PAS advocates had claimed that patients would make the decision about PAS in collaboration with a doctor with whom they had a long-standing relationship, the reality had turned out to be somewhat different. The ODHS had asked doctors how many patients had received PAS from their own doctors and how many as a result of referral by a group active in promoting PAS, such as Compassion in Dying, and had discovered that over 80% fell into the latter group. The ODHS had nevertheless excluded this discovery from its report.⁷⁵

Finally, the ADTI Report omits to note two aspects of the US experience which might be thought significant. First, since 1997 the Oregon Medical Association (while neutral on PAS in principle) has been opposed to the Oregon law.⁷⁶ Secondly, the Oregon precedent has been repeatedly rejected elsewhere in the US. One expert on the US euthanasia debate, Dr Rita Marker, has pointed out that since Oregon's law was passed in 1994 (before being held up until 1997 by an unsuccessful challenge in the courts):

⁷² N Gregory Hamilton, 'Oregon's culture of silence' in Foley and Hendin, op cit n56, supra, 175, 179.

⁷³ Ibid.

⁷⁴ Ibid, 180.

⁷⁵ Ibid, 180-181.

⁷⁶ Personal communication from Mr Jim Kronenberg, Chief Operating Officer of the OMA, 17th October 2005. His email reads:

'In 1994 the Oregon Medical Association's governing body chose to neither oppose nor support Oregon's proposed death with dignity act, which passed by a vote of the people later that year. At the same time OMA established a position of neutrality on the ethical issue of physician assisted suicide. In 1997, the Oregon Legislature chose to refer the PAS law back to the people with a recommendation of repeal. OMA supported repeal of the act based on perceived flaws in the statutory language; thereby changing its position from neutrality to opposition. Of course the people soundly defeated repeal and in 1999 the Legislature substantively addressed most (but not) all imperfections in the law identified by OMA. OMA's position of opposition to Oregon's PAS law established in 1997 has not been revisited; nor has its position of neutrality as to the concept of PAS generally.'

'at least 54 assisted suicide and/or euthanasia measures have been introduced in 21 states. Not one has passed. On the other hand, between 1995 and 1999, seven states passed laws prohibiting assisted suicide'.⁷⁷

When two members of the Committee (Baroness Hayman and Baroness Jay) asked defenders of the Oregon law why their precedent had not been followed elsewhere in the US, no cogent answer was forthcoming. (II, pp315-317, Q849-Q856) When a third member (the Earl of Arran) asked another witness from Oregon, Dr Susan Tolle of the Oregon Health and Science University, whether any other state was about to follow Oregon she replied that attempts had failed but that 'in most cases they included euthanasia as well as physician-assisted suicide'. (II, p284, Q727) Dr Tolle did not substantiate this assertion, an assertion which has been contradicted by Dr Marker who has made a study of several of these attempts.⁷⁸

3 From PAS to VAE

In its concluding chapter the ADTI Report recommends (para 269) that any future Bill should be drafted to give the House an opportunity to consider supporting PAS, VAE or both. The basis of this recommendation appears to be the Committee's view that permitting only PAS would be a way of limiting accelerated death to those most determined to obtain it (para 244), that it would be less objectionable to the medical profession, and would involve less risk of slippage to euthanasia without request (para 245). However, to permit only PAS would be problematic for several reasons.

First, the line between PAS and VAE is blurred. Writing a prescription for a lethal substance may well be an instance of the former but what of placing the lethal substance on the patient's tongue or helping the patient to keep the substance down once taken? One Committee member (Baroness Jay) touched on this point in a question to the representative from the Oregon Medical Association:

'It becomes a very grey area, does it not? If you are physically present and are taking steps to ensure that this procedure, although self-administered, is effective... not regurgitated or whatever it may be...?'

He replied: 'A very grey area'. (II, p350, Q1052-53) Similarly, the Director of the Oregon State Board of Nursing (the nursing equivalent of the OBME) told the Committee that the Board was fielding very detailed questions about the extent to which a

⁷⁷ Rita L Marker, 'Assisted Suicide: the Continuing Debate: Legislative Proposals' <http://www.internationaltaskforce.org/cd.htm#91> (Footnotes omitted). Last accessed 23rd April 2006. The omitted footnotes (15 and 16) list respectively the proposals for VAE or PAS which have been rejected and the proposals against assisted suicide which have been approved. Another website containing critical comment on the Oregon experience is run by Physicians for Compassionate Care: <http://www.pccf.org/press/press25.htm>. Last accessed 23rd April 2006.

⁷⁸ Personal communication from Dr Marker, 21 November 2005. . See Rita L Marker, 'Euthanasia and Assisted Suicide Today' (2006) 43(4) *Social Science and Modern Society* 59.

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nurse could assist the patient in taking the lethal substance and that it was a 'very grey area'. (II, p354, Q1068-69)

Secondly, it does not follow from the fact that the patient took a lethal substance that they did so volitionally. One Oregon doctor who has assisted suicide testified that the fact of self-administration 'provides a final piece of clear evidence that this is completely volitional...'. (II, p315, Q849) This does not, of course, follow. It is just as possible to pressure a patient into swallowing a lethal substance as it is to pressure them into accepting its injection. History is not short of examples of people (such as Field Marshal Rommel) being given the means to commit suicide and pressured to use them. Further, patients committing suicide with drugs provided by a doctor may be just as depressed as patients who commit suicide by jumping in front of a train.

Thirdly, the Oregon law may be held unlawfully to discriminate against those physically incapable of self-administering lethal drugs. Indeed, the deputy attorney-general in Oregon has issued an official opinion that the law may violate the Americans with Disabilities Act and may therefore need to be extended allow for lethal injections.⁷⁹

Fourthly, it does not follow (as the ADTI Report seems to imply) that the take-up rate for PAS in England and Wales would be as low as it appears to have been in Oregon. As a commentator on the Oregon law testified to the Committee:

'you would just about have to live here to truly understand why Oregon and what is unique about it. The importance of understanding some of that is you are asking if Oregon is transportable and there are some things that are very unique about us that may not be'. (II, p278, Q675)

She added:

'I do not want to say that because it has played a certain way here in Oregon...it would play out the same way in the United Kingdom, because it might not'. (II, p284, Q724)

There is surely much to be said for the view that if the law were relaxed in England and Wales our experience would be much closer to that of another densely-populated Western European country - the Netherlands - than to a sparsely populated west coast state of three and a half million people. As another witness testified, Oregon is 'a very intermediate stage and a very curious, isolated bubble'. He added:

'It is a state which exists in a rather special set of circumstances, very advantageous, well-off, isolated in many respects from the rest of the country. I have no doubt whatsoever that if the Oregon...regime were to be adopted in the wider United States it would soon prove impracticable to hold the line in the way that it has been held in the few years since Oregon's law has been in force, and we would have a movement towards the Dutch experience, extensively...'. (II, p559, Q1981)

⁷⁹ Op cit n72, 183 n29 (citing an official letter from the Oregon Department of Justice to Senator Bryant, 15th March 1999).

Why, then, was the implausible line between PAS and VAE drawn in Oregon? The answer would appear to lie in political expediency: the advocates of reform realised that PAS simply stood a greater chance of winning public acceptance than VAE. As the same witness testified, the campaign which narrowly succeeded in Oregon was one of several run

'by people who make no secret in their own publications, although it is not generally publicised, that they regard assisted suicide as simply one stage in a progressive liberation of society from its present taboo'. (II, p559, Q1981)

And the Report quotes a witness from the ODHS who testified (para144):

'they thought it might be accepted more if it was patient self-administered'.

By contrast, the Report quotes another Oregon witness who said (para 145):

'in the US we are quite a way in our community dialogue from discussing active euthanasia or injected medication to end life. We are decades away from that'.

The witness was mistaken. Proposals for active euthanasia have been discussed in the US since the early twentieth century.⁸⁰ And the campaign for the legalisation of VAE and PAS intensified with the founding in 1980 of the Hemlock Society, a leading pro-euthanasia pressure group, by Derek Humphry. Hemlock provided substantial financial backing to the campaign for the relaxation of the law in Oregon.⁸¹ Humphry and Hemlock have long advocated the legalisation not only of PAS but also of VAE. Indeed, in a letter to the *New York Times* in 1994 Humphry wrote that the Oregon law 'could be disastrous' because it did not permit lethal injections. Referring to research in the Netherlands showing that self-administered drugs often failed he wrote:

'Evidence I have accumulated shows that about 25 percent of assisted suicides fail, which casts doubts on the effectiveness of the new Oregon law...The new Oregon way to die will only work if in every instance a doctor is standing by to administer the coup de grâce if necessary.'

He observed: 'The only two 100% ways of accelerated dying are the lethal injection of barbiturates and curare or donning a plastic bag'.⁸² He also told a reporter: 'This law doesn't help the people who need it most - the people who cannot keep drugs down, because of their terrible diseases, or cannot put hand to mouth' and added: 'In a few years the law is going to have to be adapted to allow for lethal injection'.⁸³

⁸⁰ EK Emanuel, 'The History of Euthanasia Debates in the United States and Britain' (1994) 121 (10) *Annals of Internal Medicine* 793.

⁸¹ <http://www.finalexit.org/dhumphry>. Last accessed 23rd April 2006.

⁸² Derek Humphry, 'Oregon's Assisted Suicide Law Gives No Sure Comfort in Dying' Letter to the Editor, *New York Times*, 3rd December 1994.

⁸³ T Appleby, 'Suicide law falls short, activist says' *Globe & Mail*, 7th December 1994 (A10).

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There can be little doubt, then, that the explanation for the initial limitation of the Oregon law to PAS lies not in moral principle but in political tactics. The same applies to the narrowing of Hemlock's proposals to accommodate only the 'terminally ill'. As Humphry's own website explains:

'When Humphry started Hemlock, and for its first ten years of existence, the Society's credo embraced assisted dying (preferably medical) for the terminally ill and the hopelessly ill, such as patients with advanced ALS or MS, or extreme old age with severe health problems. But as Hemlock became more involved in state politics in its drive to change the law to secure physician-assisted suicide, it dropped the other illnesses and spoke only for "the advanced terminally ill." While recognizing this as necessary political expediency, Humphry stays firm in his belief that many more persons also deserve assisted dying.'⁸⁴

Clearly, only 'necessary political expediency' is holding back 'assisted dying' for a wider range of patients, and from a wider range of providers.

Fourthly, like Humphry, the Dutch have long recognised that permitting PAS but not VAE has little to recommend it either in principle or in practice. In principle, if PAS should be allowed out of respect for patient autonomy why not VAE? Practical realities also militate against drawing any such line. Dr Gerrit Kimsma, a member of a Dutch regional assessment committee who gave evidence before the ADTI Committee, has written:

'Thinking that physician-assisted suicide is the entire answer to the question of ending of life of a suffering patient... is a fantasy. There will always be patients who cannot drink, or are semiconscious, or prefer that a physician perform this act. Experience has taught us that there are many cases of assisted suicide in which the suicide fails. Physicians need to be aware of the necessity to intervene before patients awaken.'⁸⁵

He has observed that laws like those in Oregon which permit only PAS are

'headed for disaster if physicians are forbidden by law to end life actively in cases of failure of the chosen route for assistance.'⁸⁶

A Dutch study revealed that in 18% of cases in which the doctor intended to assist in suicide the doctor ended up administering a lethal injection because of complications. The study commented:

'In most of these cases, the patient did not die as soon as expected or awoke from coma, and the physician felt

compelled to administer a lethal injection because of the anticipated failure of the assisted suicide. In some cases, the physician administered a lethal injection because the patient had difficulty swallowing the oral medication, vomited after swallowing it, or became unconscious before swallowing all of it.'⁸⁷

Dr Gideonse, an Oregon doctor who has assisted suicide, told the Committee of several cases where the limitation to PAS had proved 'extremely frustrating for the patient and family' and that the provision in Lord Joffe's Bill (as it then stood) allowing for VAE made 'a lot of sense' and was an option which should be made available. (II, p315, Q849)⁸⁸

Further, if it is right that the patient's life should be brought to an end, why require an uncomfortable exit? As one medically qualified witness in Oregon testified:

'taking 90 barbiturates is not a harmless procedure: it causes vomiting; it tastes awful; it is painful. If you are going to have a quick and easy death from some kind of euthanasia or assisted suicide you have to have lethal injection...'. (II, p333, Q954)

Finally, in 2000 the British Medical Association held a conference to develop a consensus on PAS. A discussion paper written by its Medical Ethics Department considered the argument for distinguishing PAS from VAE and concluded that in many cases there was little practical difference between the two and that similar arguments against abuse applied to both.⁸⁹

The above arguments questioning the defensibility of drawing a line between PAS and VAE, arguments which are accessible in the academic literature,⁹⁰ are not mentioned in the ADTI Report.

In conclusion, the ADTI Report states (para 235) that it seeks to 'present a balanced account' of the evidence it received. Whether the Report's account of the law and practice in the Netherlands and Oregon strikes the right balance is, however, open to question, not least because the Committee heard from relatively few critics. This source of imbalance is compounded by the fact that critical evidence which *was* brought to the Committee's attention (such as the revelation by Professor Finnis about the duty on the patient in the Netherlands to make clear if he or she does not want to be euthanised) is omitted. It is suggested that a balanced and rounded understanding of the euthanasia debate, not least in respect of practice in the Netherlands and Oregon, requires familiarity not only with the ADTI Report but also with its accompanying volumes of evidence, and with other evidence besides.

⁸⁴ www.finalexit.org/dhumphry. Last accessed 23rd April 2006.

⁸⁵ Gerrit K Kimsma, 'Euthanasia Drugs in the Netherlands' in David C Thomasma *et al* (eds), *Asking to Die: Inside the Dutch Debate about Euthanasia* (Kluwer, 1998) 135, 142-143 (see Keown, 34).

⁸⁶ Idem, 'Euthanasia and Euthanizing Drugs in The Netherlands' in MP Balfin and AG Lipman (eds), *Drug Use in Assisted Suicide and Euthanasia* (Pharmaceutical Products Press, 1996) 200, 207. Quoted at: <http://www.internationaltaskforce.org/iua10.htm>. Last accessed 23rd April 2006.

⁸⁷ Johanna H Groenewoud *et al*, 'Clinical Problems with the Performance of Euthanasia and Physician-Assisted Suicide in the Netherlands' (2000) 342 *New England Journal of Medicine* 551, 554-55 (see Keown, 34-35).

⁸⁸ The President of Compassion in Dying defended the limitation to PAS 'in this society, in this state, at this time'. (II, p316, Q849)

⁸⁹ 'Euthanasia and Physician-Assisted Suicide: Do the Moral Arguments Differ?' in *Physician-Assisted Suicide Debating Pack PAS4* (BMA, 2000) 1, 4.

⁹⁰ See eg, Yale Kamisar, 'Physician-assisted suicide: the last bridge to active voluntary euthanasia' in John Keown (ed), *Euthanasia Examined* (CUP, 1995) ch 15.

II The ADTI Bill

Part II comprises three sections. Section 1 contains a summary of the ADTI Bill. Section 2 considers the extent to which the ADTI Bill has failed to incorporate several considerations identified as 'key' by the ADTI Report. Section 3 argues that, if enacted, the Bill's 'safeguards' would (as in the Netherlands and Oregon) prove inadequate to protect the vulnerable, would intensify rather than reduce pressure for further relaxation of the law, and would likely lead to the more rather than less frequent, practice of PAS.

1 A Summary of the Bill

The stated purpose of the Bill is to

'enable an adult who has capacity and who is suffering unbearably as a result of a terminal illness to receive medical assistance to die at his own considered and persistent request'.⁹¹

The sub-headings which follow track those used in the Bill.

(i) Authorisation of assisted dying

Clause 1(a) provides that it shall be lawful for a physician to assist a patient who is a 'qualifying patient' to 'die' (that is, to commit suicide) either by (i) prescribing medication or (ii), in the case of a patient 'for whom it is impossible or inappropriate orally to ingest that medication', by prescribing and providing means of self-administration. 1(b) provides that it shall be lawful for 'a person who is a member of a health care team' to 'work in conjunction' with a physician covered by paragraph (a).

(ii) Qualifying conditions

Clause 2(1) provides that before a physician may assist a patient to commit suicide, the conditions in 2(2) and 2(3) must be satisfied; the patient must have made a declaration in accordance with clause 4; and the requirements of clause 5(3) must have been met.

Clause 2(2) states that the first condition is that the physician shall have

- (a) been informed by the patient in a written request signed by the patient that the patient wishes to be assisted to die;
- (b) examined the patient and the patient's medical records and satisfied himself that the patient does not lack capacity;
- (c) determined that the patient has a terminal illness;
- (d) concluded that the patient is suffering unbearably as a result of that terminal illness;
- (e) informed the patient of –
 - (i) his medical diagnosis;
 - (ii) his prognosis;
 - (iii) the process of being assisted to die; and
 - (iv) the alternatives to assisted dying, including, but not limited to, palliative care, care in a hospice and the control of pain;
- (f) ensured that a specialist in palliative care, who shall be a physician or a nurse, has attended the patient to inform the patient of the benefits of the various forms of palliative care;
- (g) recommended to the patient that the patient notifies his next of kin of his request for assistance to die;
- (h) if the patient persists with his request to be assisted to die, satisfied himself that the request is made voluntarily and that the patient has made an informed decision; and
- (i) referred the patient to a consulting physician.

Setting out the second qualifying condition, clause 2(3) states that the consulting physician shall have

- (a) been informed by the patient that the patient wishes to be assisted to die;
- (b) examined the patient and the patient's medical records and satisfied himself that the patient does not lack capacity;

⁹¹ *Assisted Dying for the Terminally Ill Bill* (ordered to be printed 9th November 2005), Long title.

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- (c) confirmed the diagnosis and prognosis made by the attending physician;
- (d) concluded that the patient is suffering unbearably as a result of the terminal illness;
- (e) informed the patient of the alternatives to assisted dying including, but not limited to, palliative care, care in a hospice and the control of pain;
- (f) if the patient still persists with his request to be assisted to die, satisfied himself that the request is made voluntarily and that the patient has made an informed decision; and
- (g) advised the patient that prior to being assisted to die the patient will be required to complete a declaration which the patient can revoke.

(iii) Determination of lack of capacity

Clause 2(4) provides that a person 'lacks capacity' if 'at the material time' he is 'unable to make a decision for himself' in relation to assisted suicide 'because of an impairment of, or a disturbance in the functioning of, the mind or brain resulting from any disability or disorder of the mind or brain'. Clause 3(1) states that if, in the opinion of either the attending or the consulting physician, a patient seeking assisted suicide may lack capacity, the attending physician shall refer the patient to a consultant psychiatrist, or a psychologist, who shall be independent of the attending and consulting physicians, for an opinion as to the patient's capacity. According to 3(2), no assistance to end the patient's life may be given unless the psychiatrist or psychologist has determined that the patient does not lack capacity.

(iv) Declaration

Clause 4(1) provides that when the qualifying conditions have been met, a patient seeking assisted suicide must make a declaration of his wish in the form prescribed by regulations made by the Secretary of State. This declaration must (clause 4(2)) be witnessed by two people, one of whom shall be a solicitor holding a current practicing certificate or a public notary. Further (clause 4(3)) this person may witness the declaration only if the patient is personally known to him or has proved his identity to him; it appears to him that the patient is of sound mind and has made the declaration voluntarily; and he is satisfied that the patient understands the effect of the declaration. Neither the attending nor consulting physician, nor a member of the health care team, a consultant psychiatrist or psychologist consulted under section 3, nor a 'relative or partner (by blood, marriage or adoption)' of the patient may witness the declaration (4(5)). Nor (4(6)) may any person who owns, operates or is employed at a health care establishment where the patient is resident or receiving medical treatment.

(v) Duties of assisting physician

Clause 5(1) states that the physician providing assistance shall be either the attending physician or the consulting physician; 5(2) that the assisting physician shall not assist the patient to die until after the expiration of 14 days from the date on which the patient informed the physician under clause 2(2)(a) that the patient wished to be assisted to commit suicide; and 5(3) that before taking any step to assist suicide the 'existing' ('assisting?') physician shall have informed the patient (a) of his right to revoke the declaration and (b) asked the patient to confirm that the declaration has not been revoked, and has received such confirmation.

(vi) Revocation of declaration

Clause 6(1) provides that a patient may revoke his declaration orally or in any other manner irrespective of his mental state and 6(2) that the assisting (or, if there is no assisting physician, the attending) physician shall ensure that a note recording its revocation is made on the patient's file.

(vii) Conscientious objection

Clause 7(1) provides that no person shall be under any duty to participate in any diagnosis, treatment or other action authorised by the Act; or 7(3) to raise the option of 'assisted dying' with a patient, to refer a patient to any other source for obtaining information or advice pertaining to 'assistance to die', or to refer a patient to any other person for 'assistance to die' under the provisions of the Act. However, a patient shall be free to consult either an attending physician (7(4)) or a consulting physician ((7(5)) without such an objection, and such physician shall then, for the purposes of the Act, become respectively the patient's attending or consulting physician. Moreover, an attending or a consulting physician with a conscientious objection must, on receipt of a request to do so, immediately transfer the patient's medical records to the new doctor: 7(6). Clause 7(2) provides that no hospice, hospital, nursing home, clinic or other health care establishment shall be under any obligation to permit an 'assisted death' on its premises.

(viii) Protection for health care professionals and others

Clause 8 provides legal protections for those involved in 'assisted dying'. Under 8(1) no physician who 'assists a qualifying patient to die' in accordance with the Act shall be guilty of an offence. 8(2) provides that 'a member of a health care team' who 'works in conjunction with' a physician acting in accordance with the Act 'or in reliance on information supplied to him' that the requirements of the Act have been complied with shall not commit an offence. According to 8(3) a person who is present when a qualifying patient dies, having received 'assistance to die' shall not be guilty of an offence 'provided that he is present in reliance on information provided to him' that the requirements of the Act have been satisfied.

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8(4) provides that a physician covered by 8(1) or member of a health care team covered by 8(2) 'shall be deemed not to be in breach of any professional oath or affirmation'. 8(5) provides that no physician or member of a health care team may take part in 'assisting a qualifying patient to die', nor act as a witness, if he has grounds for believing that he will benefit financially or in any other way, 'except for his proper professional fees or salary', as a result of the death of the patient.

(ix) Offences

Clause 9 specifies a number of offences including the falsification, forging, concealment and destruction of declarations (9(1) and (3)), the making of witness statements known to be false (9(2)), and the participation in 'assisted dying' by physicians and members of a health care team who have grounds for believing they will benefit from the patient's death other than by way of 'proper professional fees or salary'. (9(4))

(x) Insurance

Clause 10 provides that no policy of insurance which has been in force for twelve months before the patient's death shall be invalidated because of the patient's assisted suicide under the Act.

(xi) Requirements as to documentation in medical records and reporting requirements

Clause 11(1) requires the assisting physician to ensure that the following are documented and filed in the patient's medical records: 'all evidence, data and records' which demonstrate that the qualifying conditions have been met; any written request by the patient; the declaration; and a note by the assisting physician stating that he was satisfied, at the time of giving assistance in suicide, that the Act's requirements Act had been met, and indicating the steps taken to end the patient's life including the description and quantity of medication and any means of self-administration prescribed or provided. 11(2) provides that the assisting physician shall within seven days of the patient having been assisted to die (or of an attempt to assist having been made) send a copy of each of the above documents to the monitoring commission for the region concerned.

(xii) Monitoring commission

Clause 12(1) provides that the Secretary of State shall by order establish such number of monitoring commissions in England and Wales as he may determine 'to review the operation' of the Act and 'to hold and monitor records' maintained in pursuance of the Act. According to clause 12(2) the commission(s) shall comprise three members appointed by the Secretary of State: a registered medical practitioner, a solicitor or barrister; and a lay person with 'first hand experience in caring for' a person with terminal illness. The commission shall (12(4)) confirm to the

assisting physician as soon as reasonably possible whether the requirements of the Act have been satisfied. If a majority of its members consider that the requirements of the Act have not been satisfied, the commission shall refer to the matter to the district coroner (12(3)). The Secretary of State shall publish an annual statistical report of information collected under this section (12(5)).

Clause 13 is an interpretation section. Clause 14 concerns the power of the Secretary of State to make supplementary orders and regulations as appear to him 'necessary or expedient'. Clause 15 amends the Suicide Act 1961 by inserting after section 2(3) of that Act:

'Subsection (1) [prohibiting assisting suicide] does not apply where a person assists another person to die, or where a person helps another person to assist a third person to die, or where a person is present when another person ends his own life or attempts to do so, in accordance with sections 1 and 8 of the Assisted Dying for the Terminally Ill Act 2005'.

Clause 16(2) provides that the Act shall not extend to Scotland or Northern Ireland.

2 Key Issues Addressed?

The ADTI Report identified a number of 'key issues' which it thought pertinent to the consideration of any future Bill. The Committee recommended that any future Bill should 'take account' of nine considerations. Significantly, the ADTI Bill fails to adopt several of these key considerations.

Paragraph 269(c) of the Report recommended that a future Bill should

(i) Clearly distinguish between VAE and PAS to give the House the opportunity to support one or the other or both

As we saw above (1 (3)), in Oregon there is a very grey area between PAS and VAE. Like the Oregon law the ADTI Bill allows doctors to prescribe lethal drugs. But the Bill goes further by allowing doctors to provide patients with the means to self-administer those drugs. It would therefore allow conduct bordering on VAE and create an area even greyer than in Oregon.

(ii) 'Set out clearly the actions which a doctor may and may not take' in providing assistance with suicide (or in providing voluntary euthanasia)

The previous Bill sought (clause 1(1)) to permit a physician simply to 'assist a patient...to die'. The revised Bill permits (clause 1(a)(i)) a physician to assist a patient to die by prescribing medication and (clause 1(a)(ii)) in the case of a patient for whom it is 'impossible or inappropriate' orally to ingest that medication, by 'prescribing and providing' means of self-administration. As we have just noted, it is unclear precisely how far a doctor could lawfully go.

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Further, clause 1(b) permits 'a person who is a member of a health care team to work in conjunction with a physician' to whom clause 1(a) applies. Clause 13(1) defines 'health care team' widely as a 'person or persons assisting the attending physician or the consulting physician'. Would clause 1(b) allow anyone, whether with or without medical or nursing qualifications, to work in conjunction with a physician? Is it intended to cover the pharmacist who dispenses the drugs?

And what is meant by 'work in conjunction with' a physician? Would it cover, say, a nurse or even a relative who:

- collects the drugs for the patient and delivers them?
- encourages the patient to swallow them?
- makes the drugs palatable by (say) mixing them with orange juice?
- helps the patient to swallow them (or operate any means of self-administration, as by holding up a button on a self-administration device to be pressed or helping the patient to depress the button?)
- helps the patient to keep the drugs from being regurgitated?
- helps to retrieve the drugs if regurgitated so that the patient can swallow them again?

In short, the limits on assisting a patient to commit suicide under the Bill remain obscure.

(iii) Define 'terminal illness' (if a new Bill contained such a qualifying condition) 'in such a way as to reflect the realities of clinical practice as regards accurate prognosis'

The Committee was concerned that the definition should be sufficiently precise to ensure proper protection for those who might make use of the new Act. (para 251) The previous Bill defined 'terminal illness' (clause 2) as *inter alia* an illness likely to result in death 'within a few months at most'. The revised Bill's definition reads (clause 13(1)) 'within six months'. Whether this definition reflects the realities of medical practice and is sufficiently precise is a matter for debate. First, as the Committee pointed out 'prognosis is far from being an exact science' and there can be 'wide variations from an overall norm'. (para 250) Secondly, the definition appears to include patients who could live much longer than six months if they were given treatment.

(iv) Define 'mental competence' so as to 'take into account the need to identify applicants suffering from psychological or psychiatric disorder as well as a need for mental capacity'

The Committee concluded that any definition of 'competence' needed to include two dimensions:

'that an applicant must be capable of understanding his or her situation and of reaching a reasoned decision without

external pressure; and that it must be clear that an applicant's judgement is not temporarily clouded by psychological impairment which, as is frequently the case in people who are terminally ill, may be thought transient and treatable'. (para 252)

Assisted suicide was, it noted, a matter of the 'utmost gravity' and was 'irreversible'. Society already made strenuous efforts to frustrate attempted suicides on the ground that people might think better of it at a later date and several witnesses had testified that people who ask for assisted suicide often changed their minds because they had received better palliative care or had come to terms with their situation. (para 253) The Committee therefore recommended that consideration be given to a requirement that *any* applicant for PAS (or VAE) be given a psychiatric assessment

'in order both to confirm that the request is based on a reasoned decision and is free from external pressure and that the applicant is not suffering from a psychiatric or psychological disorder causing impaired judgement',

It added that where such disorder was apparent 'we would expect an applicant to be offered treatment'. (para 254)

The Bill merely requires (clause 3(1)) that if either the attending or consulting physician thinks that an applicant may lack capacity that the patient be referred to a psychiatrist or psychologist for an opinion as to the patient's capacity. This falls far short of the Committee's recommendation, for several reasons:

- there is no requirement to refer all applicants for assessment.
- referral need only be made if there is doubt about the applicant's capacity, that is if the patient may be 'unable to make a decision' about being assisted in suicide: there is no requirement to refer if either physician thinks the patient is so capable but is nevertheless suffering from a psychiatric or psychological disorder, even one impairing the applicant's judgment.
- the fact that an applicant is competent to make a decision does not mean that the applicant's decision will be either reasoned or free from external pressure. There appears, therefore, to be no requirement of psychiatric referral if the applicant is thought competent, even if the physicians think the applicant's decision is not reasoned and has been made under external pressure.
- even if the applicant is referred for psychiatric or psychological assessment, provided the consultant is of the opinion that the patient does not lack capacity the application may proceed, even if the consultant concludes that the patient is suffering from psychiatric or psychological disorder, even one causing impaired judgment. In this respect, the current Bill is even *laxer*

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than its predecessor, clause 8(2) of which provided that no assistance in suicide could be given 'unless the psychiatrist has determined that the patient is not suffering from a psychiatric or psychological disorder causing impaired judgment, and that the patient is competent'. It is also laxer in that the previous Bill required (clause 8(1)) referral to a psychiatrist; the current Bill allows (clause 3(1)) referral to a psychiatrist or psychologist.

In April 2006 the Royal College of Psychiatrists issued a statement on Lord Joffe's Bill.⁹² It observed that few doctors were knowledgeable about assessing capacity and that many would fail to recognise that a patient lacked capacity. It added:

'If Parliament decides that this Bill should become law a very high standard of expertise would be required of those involved to both ensure that those requesting physician assisted suicide clearly had the capacity to make such a request and also, when people were considered to have this capacity, the nature of the psychological processes that had led them to make such a decision were properly explored'.⁹³

Moreover, depression frequently gained a foothold in people with physical illness and spotting it would always be challenging. This meant that PAS would put such patients at risk.⁹⁴ Depression was very common among those with painful and disabling terminal illness and studies among the terminally ill had shown clearly that depression was strongly associated with a desire for PAS and VAE. But most doctors did not recognise depression or know how to assess for its presence in the terminally ill. Moreover, once a person's depression was treated effectively most (98-99%) changed their mind about wanting to die. 'Requests for PAS should' observed the statement, 'trigger effective treatment of depression and its causes – not actual PAS'. When patients' fears and palliative care needs were addressed, requests for hastened death usually disappeared.⁹⁵ If PAS were to be permitted, the law should require at least two independent assessments. Since suicidality fluctuated, the assessments should first trigger expert psychiatric advice on treatment of depression and there should be two specialist assessments, spaced at least two months apart with offers of treatment for both depression and pain, so that there would be time for the suicidal ideation to abate.⁹⁶ The College concluded that it was 'deeply worried' by the likely effects of the Bill.⁹⁷

⁹² Royal College of Psychiatrists, *Assisted Dying for the Terminally Ill Bill – Statement from the Royal College of Psychiatrists on Physician Assisted Suicide* (2006) http://www.rcpsych.ac.uk/press/parliament/responses/Assisteddying_April06.htm (Last accessed 24th April 2006).

⁹³ *Ibid.*, 2.2.

⁹⁴ *Ibid.*, 2.3.

⁹⁵ *Ibid.*, 2.4.

⁹⁶ *Ibid.*, 3.6.

⁹⁷ *Ibid.*, 3.

(v) Consider including 'unrelievable' or 'intractable' rather than 'unbearable' suffering or distress

The Report stated that this recommendation

'would enable a more objective medical assessment to be made of a patient's suffering and should ensure that all available steps were taken to relieve distress before an application for assisted suicide or voluntary euthanasia could move forward'. (para 256)

It added:

'A test of "unrelievable" suffering might ensure that an application would not be taken at face value but that action would be taken to attempt to relieve any suffering and that only in those cases where this was unsuccessful would assisted suicide or voluntary euthanasia be considered further'. (para 256)

'Unbearable suffering' is defined (clause 13(1)) as 'suffering whether by reason of pain, distress or otherwise which the patient finds so severe as to be unacceptable'. In short, the criterion remains subjective; there is no requirement that the suffering be 'unrelievable'.

(vi) Consider how patients seeking to end their lives might experience palliative care before taking a final decision

The Report noted Lord Joffe's suggestion that VAE/PAS 'should be considered only as a last resort' (para 258, referring to II, p48, Q70, where Lord Joffe said: 'We would think that palliative care is the first option and assisted dying would normally be the last resort option'). The Committee agreed, commenting: 'We would support this view in the event that there were to be a change in the law.' (para 258) There is, however, nothing in the Bill requiring PAS to be a last resort.

The Report cited the testimony of witnesses who observed that the provision in the Bill for a meeting between the patient and a palliative care doctor or nurse was unrealistic and did not reflect the reality of palliative care practice. It quoted the testimony of a Nurse Consultant in palliative care who asked whether the real purpose of the then Bill's prescribed meeting between patient and palliative care doctor or nurse was

'to complete a requirement for the process of attaining assisted dying or to assess how a person's suffering may be supported, and if possible relieved, through palliative care. If it is the former, it is not a palliative care assessment. If it is the latter, then assessment takes, at the very least, a week and, in proportion to the severity of the suffering experienced, may take months'. (para 257 quoting II, pp150-151, Q354)

The Report also cited evidence from Help the Hospices that 'experience of pain control is radically different from the promise of pain control'. (para 258 quoting II, p702) The Committee concluded:

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'Clearly...something more than a simple consultation with a palliative care doctor or nurse is needed if patients contemplating assisted suicide or voluntary euthanasia are to be able to make fully informed choices',

adding

'If...a future bill is to be able to claim with credibility that it is offering assistance with suicide or voluntary euthanasia as complementary rather than as an alternative to palliative care, it may need to find a way of resolving this dilemma'. (para 258)

The Bill merely requires that the attending physician has ensured that a doctor or nurse specialist in palliative care has attended the patient 'to inform the patient of the benefits of the various forms of palliative care' (clause 2(2)(f)) and that the consulting physician has informed the patient 'of the alternatives to assisted dying including, but not limited to, palliative care, care in a hospice and the control of pain' (clause 2 (3)(e)). It would therefore seem that the Committee would regard the terms of the new Bill as insufficient to ensure that patients would be making fully informed choices, and that it would conclude that the Bill cannot with credibility claim to be offering PAS as complementary to rather than as an alternative to palliative care.

(vii) Seek, in setting a waiting period between an application for assisted suicide or voluntary euthanasia and their implementation, to balance the need to avoid increased suffering for determined applicants against the desirability of providing time for reflection for the less resolute

The Report cited the concern of the National Council for Hospice and Specialist Palliative Care Services (NCHSPCS) that consideration should be given to requiring a waiting period after the declaration has been signed to 'enable the patient to focus not on the process of qualifying for and making a declaration but on the decision whether then to proceed'. (para 259) The Committee acknowledged the force of the concern that patients should, in their own interests, be prevented by law from acting without reflection 'or even from feeling subconsciously that, having proceeded as far as the signing of a declaration and having put a number of people to a lot of trouble, he or she should not draw back'. (para 260) It expressed the view that need for a 'cooling off' period would seem 'less important' in a Bill proposing to permit only PAS and not VAE 'as the evidence we received in Oregon suggested that many of those who receive lethal prescriptions do not immediately ingest them but rather keep them as a form of insurance policy'. (para 260) However, it does not follow that this would also be the case in England and Wales and, even if it would, requiring a waiting period would help those who might otherwise feel pressured and would do nothing to prejudice those who wanted keep the drugs as an 'insurance policy'.

Notwithstanding the concerns expressed by the Committee, the waiting period in the Bill remains 14 days from the time the

patient informed the attending physician of his or her wish for PAS. (clause 5(2))

(viii) Should not place on a physician with conscientious objection the duty to refer an applicant for assisted suicide or voluntary euthanasia to another physician without such objection; should provide adequate protection for all health care professionals who may be involved in any way in such an application, and should ensure that the position of persons working in multi-disciplinary teams is adequately protected

Clause 7(1) of the Bill provides that 'No person shall be under any duty to participate in any diagnosis, treatment or other action authorised by this Act, apart from subsection (6), to which he has a conscientious objection.' 7(6) requires the attending or consulting physician with a conscientious objection immediately, on receipt of a request to do so, to transfer the patient's medical records to the patient's new physician. The previous Bill placed a duty to refer on the attending doctor (clause 7(2)) or consulting doctor (clause 7(3)) who had conscientious objection. The Committee noted concerns expressed by the Joint Committee on Human Rights that such a duty might violate article 9(1) of the European Convention on Human Rights.(para 261) The present Bill therefore provides (clause 7(3)):

'No person shall be under any duty to raise the option of assisted dying with a patient, to refer a patient to any other source for obtaining information or advice pertaining to assistance to die, or to refer a patient to any other person for assistance to die under the provisions of this Act'.

The Bill also goes further than the previous Bill in providing (clause 7(2)) that 'No hospice, hospital, nursing home, clinic or other health care establishment shall be under any obligation to permit an assisted death on its premises'.

The Committee was also concerned to protect the conscientious objection of 'all members of the clinical team'. It stated:

'In particular, it should seek to address such situations as that in which, for example, a nurse with conscientious objections is asked by a patient to raise with a doctor on his or her behalf a request for assisted suicide or voluntary euthanasia'. (para 262)

The scope of protection afforded by the new Bill is clearly wider than that of the previous Bill. However, it is not clear how far it would extend. For example, despite the fact that the Committee specifically recommended that the nurse in its hypothetical case should be protected, it is doubtful whether she would be covered either by clause 7(1) or 7(3). And what (say) of a doctor's secretary asked to type a referral letter? Would she thereby be asked 'to participate in any diagnosis, treatment or other action authorised by this Act' within clause 7(1)? Perhaps. But a court might deny her protection, either on the ground that she would not be 'participating' in an action which had been authorised by the Act or that her act of typing the letter

was not 'authorised' by the Act because it was already lawful. In the *Janaway*⁹⁸ case the House of Lords held that a medical secretary asked to type a referral letter for an abortion was not protected by the equivalent section of the Abortion Act 1967, section 4(1), which provides that no person shall be under any duty to participate in any treatment authorised by that Act. The Law Lords held that 'participate' should be given its ordinary meaning of 'taking part' in the abortion and that as the secretary could not be said to be 'taking part' in the abortion, she could not claim conscientious objection to writing the referral letter. The wording of clause 7(1) is wider than section 4(1) of the Abortion Act since it refers not only to diagnosis and treatment but to 'any other action'. However, a court might hold that these words refer to actions closely related to diagnosis or treatment, such as setting up equipment for the patient to be able to self-administer a lethal dosage, and not to remoter actions such as typing a referral letter. In favour of this interpretation is the fact that clause 1, which deals with the 'Authorisation of assisted dying', provides that it shall be lawful for a 'physician' to do certain acts (clause 1(a)) and for 'a person who is a member of a health care team' to work 'in conjunction with' (clause 1(b)) a physician to whom clause 1(a) applies. 'Health care team' is rather widely defined in clause 13(1) as 'a person or persons assisting the attending physician or the consulting physician' but this might reasonably be interpreted to exclude laypersons. The alternative analysis which would also deny the secretary the protection of clause 7(1) would be that she would not be participating in conduct 'authorised' by clause 1 because, under the present law, typing a referral letter does not require such authorisation. Her intention in typing the letter would be to comply with the conditions of her employment and not to assist suicide. It would not, therefore, be unlawful, and would not, therefore, be 'authorised' by clause 1.

The position of the nurse in the Committee's hypothetical case, and of the medical secretary, is, then, unclear. (Indeed, the interplay not only of clauses 1 and 7, but of 1,7, 8 and 15 of the ADTI Bill is far from transparent.)

(ix) Should not include provisions governing the administration of pain relief by doctors

The previous Bill (clause 15) gave patients a right to receive such pain medication as necessary to keep them free as far as possible from pain and distress. The Committee noted criticisms of this provision by the NCHSPCS and the BMA and identified practical objections of its own. (paras 265-266) Lord Joffe proposed to withdraw it and the current Bill contains no such provision. It may be noted in passing that in a number of other jurisdictions there is a statutory duty to provide palliative care and that the case for something similar in English law, given evidence suggesting widespread under-provision of pain-relief, is perhaps stronger than the Committee thought.

To conclude this section, the revised Bill has taken on board some, but by no means all, of the Committee's key considerations.

3 A Critique of the Bill

Broadly, the Bill is modelled on the Oregon statute with the addition of part of the Dutch monitoring system. The Bill is, therefore, vulnerable to similar objections to those which have been levelled against the law in those two jurisdictions. In particular, the principles underlying the Bill call for its extension, and its 'safeguards' would prove ineffectual in practice.

(i) Slippage in principle

The Bill carries the seeds of its own extension from assisted suicide for the terminally ill who are suffering unbearably to active euthanasia on request and, in due course, without request. The limitations in the Bill seem little more than arbitrary lines in the sand.

Lord Joffe told the Select Committee (referring to the Bill as it then stood):

'The Bill is based on the principle of personal autonomy and patient choice, the right of each individual to decide for themselves how best he or she should lead their lives.' (II, p47, Q70)

Personal autonomy was the 'key principle' underpinning the Bill. (II, p50, Q70; the 'underlying principle' (II, p52, Q73); 'underlying it all, is the patient's autonomy' (II, p56, Q104)). But if personal autonomy is the key principle why should patients have to be 'terminally ill' to qualify for PAS? Indeed, Lord Joffe, noting that the Bill had been criticised by some for not being more permissive, admitted to the Select Committee:

'...we are starting off; this is a first stage; it is new territory....[N]ormally with new legislation one should go forward in incremental stages. I believe that this Bill should initially be limited, although I would prefer it to be of much wider application....' (II, p53, Q89)

He testified that it was 'a first stage and possibly the final stage but there could be subsequent stages'. (II, p57, Q122) He admitted that the limitation of the Bill to the terminally ill was due simply to the strength of opposition encountered by the previous Bill which was not so limited, and he added:

'I can assure you that I would prefer that the law did apply to patients who were younger and who were not terminally ill but who were suffering unbearably, and if there is a move to insert that into the Bill I would certainly support it'. (II, p58, Q124)

Terminal illness would not be the only limit to fall victim to the principle of autonomy. If individual autonomy is key how can the Bill permit PAS but not VAE? How, moreover, can it deny either PAS or VAE to those who want accelerated death and

⁹⁸ *Janaway v Salford AHA* [1988] 3 All England Law Reports 1051, HL.

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who are not suffering unbearably or even at all? Further, the Bill limits PAS (clauses 1(a) and 13(1)) to those who have attained the age of majority. Why does it not respect the autonomous requests of legally competent patients under 18, as do the Dutch?

A second reason why the Bill carries the seeds of its own extension is that there is a second principle underlying the Bill. Although Lord Joffe placed autonomy centre stage, the principle of beneficence (that one ought act to benefit others) is lurking in the wings. Indeed, he testified that the Bill was a 'deeply humane piece of legislation...'. (II, p51, Q70) Lord Mackay noted that the Bill did not cover those who were suffering unbearably but who were incompetent, to which Lord Joffe replied that the Bill was based on the principle of autonomy. (II, p56, Q107-108) Lord Mackay pointed out:

'Your Bill is also based on the principle of humanity, you have explained to us, and that would apply to the incompetent as well as the competent.' (II, p56, Q109)

If respect for autonomy requires assisted suicide for patients competent to request it why doesn't beneficence (humanity) require euthanasia for those who are not competent? Further, like autonomy, beneficence undermines the limitation of assisted suicide to those suffering unbearably with six months or less to live. If it is humane to assist such patients is it not even more humane to assist those who face longer periods of unbearable suffering? Moreover, like autonomy, beneficence undermines the requirement that the patient be suffering 'unbearably'. Is it not humane to put an end to suffering which the patient could bear but does not wish to? Again, like autonomy, beneficence sees little justification in limiting accelerated death to those whose suffering arises from an illness, terminal or otherwise. Illness is one, but (as we all know) by no means the only, source of human suffering. Finally, like autonomy, beneficence would permit PAS or VAE for those who are suffering even if they were under 18.

Thirdly, it seems that Lord Joffe, like many advocates of VAE/PAS, sees little, if any, moral difference between PAS and other end-of-life decisions which shorten life. He testified:

'there are a number of other end-of-life decisions which take place; such as withholding treatment, and withdrawing treatment. There are also decisions taken, indeed, in relation to double effect which have the effect of ending a person's life, and there are decisions taken in relation to terminal sedation which in my view are indistinguishable from assisted dying as we have defined it. In all these cases, there is no legislation; no safeguards whatsoever.... And these decisions are end-of-life decisions, just as assisted dying is, so it is disturbing that all these objections are raised in relation to assisted dying and not raised in relation to these other end-of-life decisions...'. (II, p54, Q98. See also II, p316, Q854.)

But if what matters morally to Lord Joffe is the shortening of life, and if he accepts the shortening of the lives of patients,

competent and incompetent, by the withholding/withdrawal of treatment, then he must surely accept the shortening of the lives of patients, competent and incompetent, by lethal injection. In his testimony, he certainly voiced no objection to NVAE in principle. He stated:

'For people who are mentally incompetent there needs to be, perhaps, a different system, but it cannot be based... on personal autonomy'. (II, p56, Q108)

In short, the Bill's limitations (to PAS, 'terminal illness', 'unbearable suffering' and adults) seem, as in Oregon, little more than political expediency, temporary concessions designed to coax The Lords to take the first step onto a precipitous slope. If that step were taken, the limitations would soon buckle before the inexorable pressure of the very same principles, autonomy and beneficence, which were invoked to justify that first step.

(ii) Slippage in practice

(a) The Bill's 'safeguards'

Lord Joffe claimed to the Select Committee that his Bill 'contains an array of safeguards to protect people who could be vulnerable' (II, p47, Q70) and that it is 'considerably more restrictive and has more safeguards' than the laws in the Netherlands, Belgium or Oregon. (II, p48, Q70) In some respects, the Bill is more restrictive than those laws. Unlike Oregon it requires 'unbearable suffering' and unlike the Netherlands it does not permit VAE. But in other respects the Bill is less restrictive. The Oregon law does not allow PAS for those suffering 'a psychiatric or psychological disorder, or depression causing impaired judgment'.⁹⁹ The Bill, by contrast, permits PAS for those who merely do not 'lack capacity': there is nothing in the Bill to prevent PAS for those who are 'capable' but whose judgment is impaired by psychiatric disorder. Again, Dutch law requires doctors who have performed VAE/PAS to be interviewed by the local medical examiner whereas the Bill requires no interview. Further, the Dutch guidelines require VAE/PAS to be a 'last resort'. Even though this guideline has been loosely interpreted in practice to include cases where palliative care could have alleviated pain but was refused by the patient, it nevertheless reflects some attempt to rule out VAE/PAS as an earlier or even first resort. There is nothing in the ADTI Bill requiring PAS to be last resort or for the patient to have tried palliative care.

Even to the extent that the Bill contains further 'safeguards' than the Oregon law on which it is modelled those 'safeguards' would do little to protect the vulnerable. First, the Bill's most significant addition to the Oregon law, the incorporation of part of the Dutch monitoring process, does little to allay concern. The Bill neither provides how many such commissions there are to be nor gives them powers of investigation. As we have seen, the Dutch monitoring process (both before and after the establishment of the regional review committees in 1998) has

⁹⁹ Death with Dignity Act 127.825 s.3.03.

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comprehensively failed to detect widespread abuses. This is so even though, as we have just noted, the Dutch system is stricter than the Bill in requiring the doctor to be interviewed by the local medical examiner. Is there any reason to suppose that, as in the Netherlands and Oregon, the 'monitoring' process would amount to any more than a self-validating exercise in box-ticking by those who chose to report?

Secondly, the Bill, unlike the Oregon law, requires (clause 2(2)(d)) the patient to be 'suffering unbearably'. However, this seems to be an essentially subjective criterion. Lord Mackay asked whether 'the "unbearable suffering" definition depended on the patient's subjective view of the matter?' to which Lord Joffe replied: 'It does'. (II, p60, Q139) Lord Joffe added the proviso that it be 'reasonable' for the patient to have reached the conclusion that the suffering is unbearable. (II, 60, Q142) This seems inconsistent with his answer to Lord Mackay and with his earlier testimony that 'it is not for the physician to decide whether the patient has made a wise or unwise decision...'. (II, p48, Q70) In any event, there is nothing in the Bill requiring the patient's opinion to be 'reasonable'. Moreover, the elasticity of the notion of 'unbearable suffering' is well illustrated in the Netherlands where, it will be recalled, it has been stretched by the courts beyond physical illness to include grief at the loss of loved ones.

Other supposed 'safeguards' in the Bill, such as the requirement (clause 4(3)(a)) that the patient's declaration be witnessed by someone to whom the patient is known or to whom the patient has proved his identity, also fail to impress. As Lord Carlile put it to Lord Joffe in Committee:

'there is a huge difference between someone being personally known to a witness, which presumably means known not merely as to identity, and simply identifying them. Otherwise, it is a virtually valueless provision...'. (II, p53, Q86)

Lord Carlile went on:

'Identifying someone as who they are and their appearing to be of sound mind does not require any in-depth knowledge of that person, does it?' (II, p53, Q88)

Lord Joffe replied: 'There is no intention that they should have in-depth knowledge of that person'. (II, 53, Q88)

(b) A hypothetical case: Clare

A hypothetical case may help to show why any description of the Bill's safeguards as 'strict' would be wide of the mark.

Clare is a 75 year-old woman with incurable breast cancer. Her life expectancy, without treatment, is just under six months and, with treatment, two years.

(The Bill's definition of 'terminal illness' in clause 13(1) as one which *inter alia* 'cannot be reversed by treatment (although treatment may be successful in relieving symptoms temporarily)' would appear to extend to terminal illnesses which would not, with treatment, result in death within six

months. Lord Mackay asked Lord Joffe: 'some of these illnesses anyway can have considerable, what is described as, "remission". Is that intended to be covered by 'relieving symptoms temporarily' by treatment?' Lord Joffe replied: 'Yes'. (II, p60, Q138))

'Qualifying patient' is defined *inter alia* (clause 13(1)) as a patient who has 'been registered for primary health care in England and Wales for a period of at least twelve months...'. Lord Joffe testified that this is 'to stop tourists coming to the United Kingdom to avail themselves of this facility'. (II, p49, Q70) He did not explain why, if nationals of other member states of the EU are entitled to access healthcare in this country, they could lawfully be denied this medical intervention. It must be doubtful whether this limitation could withstand a challenge under EU law.)

Seriously depressed, she feels suicidal. Roger, her estranged brother, only surviving relative and sole beneficiary of her estate which includes a sizeable life-insurance policy she took out just over a year ago, encourages her to consider PAS. He finds in the Yellow Pages a clinic whose advertised services include 'assisted dying' and makes an appointment for Clare the following day. At the clinic, Clare sees Dr Gray. Clare tells Dr Gray that she is 'suffering unbearably' from her illness. Dr Gray examines her and reads the medical records Clare has brought with her. He says he has no reason to doubt what they say (that she is terminally ill and likely, without treatment, to die within six months) nor what she says (that she is suffering unbearably). He raises and recommends the option of assisted suicide. Clare mentions that her usual GP has repeatedly refused to assist her. Dr Gray does not bother to contact her GP.

(Lord Joffe testified that 'it is the patient who must initiate the request for assistance to die, not the physician...'. (II, p48, Q70) With respect, of course it is: how could the *physician* request assisted suicide? And this is not to say that the physician may not raise the option of assisted suicide. Indeed, Lord Joffe testified that if a patient does not raise the matter and is suffering unbearably toward the end of life 'there would be a duty on the doctor to raise this as one of the other options – not the preferred option, but an option that exists'. (II, p59, Q131) There is indeed nothing in the Bill to prevent the physician from raising assisted suicide or even strongly recommending it.)

Clare then hands Dr Gray a letter, dictated by Roger and signed by herself, requesting assisted suicide. Dr Gray gives her a leaflet describing the process of assisted suicide under the Act and alternatives to it. He calls in a clinic nurse who has undergone a course in palliative care and who gives Clare a leaflet about the benefits of palliative care.

(A 'specialist in palliative care' in clause 2(2)(f) is not defined by the Bill, and it does not seem unreasonable to interpret it as including such a nurse. The previous Bill required (clause

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3(1)) a discussion with the patient of the 'option' of palliative care. In Committee Lord Mackay asked:

'One would expect...that before a patient got into the situation of considering anything along the lines of this Bill, he or she would have experienced such palliative care as it was possible to provide?'

Lord Joffe accurately replied: 'I am not sure that is actually the position'. (II, p60, Q146) Nor is it the position under the present Bill, which does not require the patient to have experienced any palliative care.

Lord Joffe claimed that the 'offer' of palliative care in clause 3 as it previously stood was 'unique' compared to countries with 'assisted dying'. (II, p49, Q70) However, clause 3 did not contain an 'offer' of palliative care, merely a discussion of the 'option' of palliative care. And the revised Bill refers only to the provision of information about its benefits. The Dutch guidelines require VAE/PAS to be a 'last resort', though the practice has shown that is frequently anything but.)

Dr Gray encourages Clare to notify her next of kin (Roger). Clare repeats that she wants PAS. The consultation, which has lasted a quarter of an hour, comes to an end. Dr Gray then asks her to pop next door to see another doctor at the clinic, Dr White.

(The Bill requires (clause 13(1)) the 'consulting physician' to be 'independent' of the attending physician. Lord Joffe testified that 'independence seems to mean that there is no financial relationship...between the two'. (II, p59, Q134) There need surely be no 'financial relationship' between Dr Gray and Dr White, whether they are independent contractors or whether they are both salaried employees of the clinic. Similarly, it appears that the psychiatrist or psychologist referred to in clause 3(1) could be employed by the same clinic as the attending and consulting physicians and still qualify as 'independent'.)

Clare sees Dr White, an oncologist, and repeats her request for PAS. Dr White examines her and reads her medical records. He agrees with Dr Gray's diagnosis and prognosis, that she does not lack capacity and that she is suffering unbearably. He informs her of the alternatives to PAS. Clare repeats her request for PAS, which Dr White says he believes to be voluntary and informed. He tells her that prior to receiving her prescription for lethal drugs she will need to complete a declaration, which she can revoke if she wishes.

(The 'consulting physician' is defined by clause 13(1) as 'a consultant physician who is qualified by specialty to make a professional diagnosis and prognosis regarding the patient's illness and who is independent of the attending physician'. It is not clear whether 'consultant' physician means a physician who holds the rank of consultant in the National Health Service (even though he or she may also be in private practice) or whether it might include any doctor who gives a second

opinion. The previous Bill confined 'consulting physician' (clause 1(2)) to a 'consultant physician practising in the National Health Service'. The present Bill contains no such limitation. Nor is it clear what 'qualified by specialty' means. Does this require particular qualifications and, if so, which, or is it satisfied by a doctor's experience in a certain area and, if so, what type and length of experience?)

After this second consultation, which has also lasted little more than fifteen minutes, Dr White suggests to Clare that she might like to make her declaration at the nearby solicitors, Smiths, and to return for her prescription in two weeks' time, together with a cheque for a thousand pounds.

(Like most doctors, neither Dr Gray nor Dr White has expertise in psychiatry and they fail to notice the symptoms of Clare's depression. Even if they had, the Bill requires a patient to be referred for assessment by a psychiatrist or psychologist only if either doctor thinks the patient may 'lack capacity'. Lord Mackay asked:

'Should they not also seek psychiatric advice if there is any possibility in their minds that the patient is suffering from some psychiatric or psychological disorder that could impair their judgment?'

Lord Joffe replied that the patient should be referred only if the disorder could affect their competence. (II, p61, Q150)

The Bill also provides by clause 8(1) that a physician who assists a patient to die under the Act (or, by 8(2) a member of a health care team working in conjunction with a physician) 'shall not, by so doing, be guilty of an offence'. Would this clause insulate physicians who were seriously negligent in providing a lethal prescription (by, for example, overlooking obvious evidence that the patient was not terminally ill, or was not competent) from liability for gross negligence manslaughter? If so, why should such grossly negligent conduct be protected? Finally, even if either Dr Gray or Dr White had refused her application, there would be nothing in the Bill to prevent Clare from 'shopping around' for more a compliant doctor.)

Clare goes straight to Smiths, who are solicitors to the clinic, who see many applicants referred by the clinic, and who are happy to oblige her. She produces her pension book as proof of identity and her declaration is witnessed by a young solicitor and his secretary. Unbeknown to Clare, the solicitor, Tom, is a good friend of Roger's and the secretary, Liz, is Roger's girlfriend. Two weeks later, Clare returns to the clinic. Dr Gray informs her of her right to revoke her declaration and asks whether she has revoked the declaration. Clare replies she has not. Dr Gray gives her a prescription for a lethal dosage of drugs and then files a report with the monitoring commission stating that the requirements of the Act have been satisfied. When she gets home, Clare informs Roger that she has obtained a lethal prescription under the Act. Roger says he thinks she has

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done the right thing, offers to have it filled for her, and promises to be present when she decides to take drugs.

Eighteen months later (the doctors' prognosis of death within six months having proved inaccurate) Clare's depression has intensified, so much so that she is now legally incompetent. Not having experienced palliative care, she is also in considerable, unrelieved pain. She takes to her bed. With Roger standing over her, she takes the drugs. She vomits some of the capsules up, retrieves them and swallows them again. After several lingering hours, Clare dies.

(Clause 8(3)(a) provides that a person who is present when a qualifying patient dies, having received assistance to die 'shall not be guilty of an offence provided that he is present in reliance on information provided to him that the requirements of this Act in relation to the patient have been complied with'. As noted above (II, 2 (ii)) It is not clear how far the protection afforded by this provision would extend. Would it include presence intended to encourage the patient to commit suicide, whether out of compassionate or malicious motives? Would it permit those present to give encouragement by word ('Go on, Clare, swallow the capsules') or by action ('I'll hand you the pills one by one Clare' or 'I'll mix the pills with some orange juice to make them easier for you to take' or 'I'll help you keep them down by putting my hand over your mouth')? And if, say, a relative who is present overlooks obvious signs that the patient is mentally incompetent but does not take reasonable steps to stop the patient from committing suicide, does clause 8(3) insulate them from possible liability for gross negligence manslaughter?)

Shortly after, Roger inherits Clare's estate.

(It is difficult to see how the monitoring commission would have any ground for notifying the coroner in this case since Dr Gray has informed the commission that all the requirements of the Act have been satisfied. And in the unlikely event that criminal proceedings were launched against Dr Gray or Dr White the prosecution would have an impossible task proving non-compliance for the terms of the Act have indeed been satisfied. Lord Joffe testified that in criminal proceedings the burden would be on the doctor to prove compliance with the Act. (II, p57, Q113) There is, however, nothing in the Bill to reverse the rule that the burden of proof rests on the prosecution. In prosecutions for procuring a miscarriage outwith the terms of the Abortion Act 1967 the burden of proof rests on the prosecution: *R v Smith*.¹⁰⁰ Moreover, according to the evidentiary rule of strict construction, any ambiguity in the terms of the new Act would likely be construed in favour of the accused.)

We may conclude our unsettling hypothetical case by noting that there appears to be nothing in the Bill to prohibit Clare from taking the lethal drugs in her local McDonalds or, had Clare not

taken the drugs and died naturally, to ensure that the drugs are taken into safe keeping.

(iii) Slippage and cultural change

As Clare's case illustrates it would be a mistake to imagine that if the ADTI Bill were passed it would allow PAS only in 'hard cases' of dying patients with unrelievable suffering whose judgment was unimpaired by psychological disorder. It would equally be a mistake to think that, if the Bill were passed, everything else would remain the same. Legislation often has effects far beyond those intended or envisaged by those who enact it. The very passage of the Bill would likely set in motion a cultural shift, radically transforming attitudes, both in the medical profession and in society generally. PAS, far from being punishable by imprisonment and erasure from the medical register, would become, as in the Netherlands and Oregon, a legitimate therapeutic option, part of the medical mainstream. In everyday practice, the question facing doctors, patients and relatives would no longer be 'Why PAS?' but 'Why not PAS?' Why bother with time-consuming palliative care for the terminally ill when the quick, easy fix of PAS would be at hand? It would also be naïve to suppose that the potential financial savings from PAS would escape the attention of cost-conscious policy-makers and health service managers.

Those who think such a cultural shift fanciful should consider the effects of a comparable piece of legislation: the Abortion Act 1967. When this law was being debated in Parliament there was much talk of 'hard cases' (such as victims of rape, mothers 'worn out' by multiple childbirth,...), widespread breach of the existing law ('backstreet' abortions allegedly running into six figures) and of 'safeguards' in the proposed new law which would prevent abuse (second medical opinions and notification to the Department of Health). And the subsequent reality? Abortion available on request, carried out in over 180,000 cases per year and in most cases, as those who perform them admit in their published papers, not on 'health' grounds, as required by the Act, but on 'social' grounds.¹⁰¹ At the time of the passage of the Abortion Act, the Act's sponsor, David (now Lord) Steel stated it was 'not the intention of the promoters of the Bill to leave a wide open door for abortion on request'.¹⁰² Some fifteen years later, he admitted: 'Abortion is, I am afraid, being used as a contraceptive'.¹⁰³

As Lord Habgood perceptively observed in 1974:

'Whatever the rights and wrongs concerning the present practice of abortion, there is no doubt about two consequences of the 1967 Act:

- (a) The safeguards and assurances given when the Bill was passed have to a considerable extent been ignored.

¹⁰⁰ [1974] 1 *All England Law Reports* 376, CA.

¹⁰¹ John Keown, *Abortion, Doctors and the Law* (CUP, 1988) ch 5.

¹⁰² (1966-67) 732 *Parliamentary Debates*, HC, 1067, 1075.

¹⁰³ Peter Bartam, *David Steel: His Life and Politics* (WH Allen, 1982) 85.

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- (b) Abortion has now become a live option for *anybody* who is pregnant. This does not imply that everyone who is facing an unwanted pregnancy automatically attempts to procure an abortion. But because abortion is now on the agenda, the climate of opinion in which such a pregnancy must be faced has radically altered'.¹⁰⁴

He continued that one could expect 'similarly far-reaching and potentially more dangerous consequences from legalized euthanasia'.¹⁰⁵ The force of his argument is hardly diminished in relation to the legalisation of PAS, not least when it is realised that PAS is merely a stepping-stone to euthanasia with and, in time, without request. Similarly, Lord Goff, the former Law Lord, commenting on the difficulty of drawing a defensible line permitting VAE in certain circumstances, has written:

'An indication that there may well be no such defensible line may be drawn from experience of the legalisation of abortion in England which, though introduced for the main purpose of attacking the perceived evil of back street abortions, now extends to permit abortion in practically all circumstances'.¹⁰⁶

In the House of Lords debate on the ADTI Report Lord Habgood reprised his argument. He observed:

'The central point is that as new practices become familiar, the culture changes, and that has consequences for the way people think about themselves. We may imagine that we are making an autonomous choice, when in fact we are merely responding to changed social expectations; as is all too obvious nowadays in the choices made about abortion'.¹⁰⁷

In a book edited by a leading advocate of PAS, Professor Margaret Battin, this phenomenon of cultural change is explored in a chapter by Professor Patricia Mann. Professor Mann (whose chapter expresses no moral objection to PAS) observes:

'Autonomy, understood as freedom from interference of others, ceases to be a meaningful value insofar as it

ignores the fabric of relationships, good and bad, within which our actions necessarily occur'.¹⁰⁸

She adds (writing of the US, though her argument applies with hardly less force to England and Wales) that if PAS were to be legalised:

'many doctors will adjust their practices, and gradually their values, as well... Insofar as assisted suicide is a cost-efficient means of death, doctors are also likely to be rewarded by healthcare companies for participating in it. As institutional expectations and rewards increasingly favor assisted suicide, expectations and rewards within the medical profession itself will gradually shift to reflect this. Medical students will learn about assisted suicide as an important patient option from the beginning of their training. We may expect that a growing proportion of doctors will find themselves sympathetic to this practice, and will find themselves comfortable with recommending it to their patients'.¹⁰⁹

Families, she adds, will also be affected by legalisation:

'Once assisted suicide ceases to be illegal, its many advantages to busy relatives will become readily apparent. More than merely an acceptable form of ending, relatives and friends may come to see it as a preferred or praiseworthy form of death'.¹¹⁰

In this changed climate of opinion, she observes, 'A lingering death may come to seem an extravagance, a frivolous indulgence'.¹¹¹ She adds

'strong social expectations are likely to develop for individuals to choose assisted suicide as soon as their physical capacities decline to a point where they become extremely dependent up on others in an expensive, inconvenient way'.¹¹²

In the same book, Professor Battin supports a 'sea-change' in attitudes to death and dying toward one based on autonomy and she honestly acknowledges that if this change comes about, 'the widespread assumption that PAS would or should be rare collapses'.¹¹³

¹⁰⁴ Rt Rev JS Habgood, 'Euthanasia – A Christian View' (1974) 3 *Journal of the Royal Society for Health* 124, 126 (original emphasis).

¹⁰⁵ *Ibid.*

¹⁰⁶ Lord Goff, 'A Matter of Life and Death' (1995) 3(1) *Medical Law Review* 1, 14.

¹⁰⁷ (2005) 674 *Parliamentary Debates*, HL, col 135.

¹⁰⁸ Patricia S Mann, 'Meanings of Death' in M Battin *et al*, *Physician-Assisted Suicide: Expanding the Debate* (Routledge, 1998) 11, 19,

¹⁰⁹ *Ibid.*, 21.

¹¹⁰ *Ibid.*, 21-22.

¹¹¹ *Ibid.*, 23.

¹¹² *Ibid.*, 25.

¹¹³ Margaret Battin, 'Physician-Assisted Suicide: Safe, Legal, Rare?' in Battin *et al*, *op cit* n108, *supra*, 63, 71.

Conclusion

The ADTI Report contains valuable insights into the debate about PAS and VAE, not least in relation to the state of current public opinion and medical practice. But a fuller and more rounded appreciation of the debate requires the Report to be read together with its accompanying volumes of evidence¹¹⁴ and more evidence besides. In particular the Report, read on its own, tends to paint too benign a picture of the law and practice in the Netherlands and Oregon. That picture largely reflects the testimony of the witnesses whose evidence the Committee received, many of whom were involved in promoting or implementing PAS and few of whom had objections to PAS; it also reflects the omission of some critical evidence which was brought to the Committee's attention.

As Part II showed, the ADTI Bill has failed to incorporate a number of key considerations identified by the ADTI Report. For this and other reasons the ADTI Bill is vulnerable to many of the criticisms levelled at the laws overseas on which it has borrowed. Being based broadly on the lax Oregon law, with an

admixture of the ineffectual Dutch monitoring system, the Bill would expose patients (not least the most vulnerable) to the risk of abuse. As the Royal College of Psychiatrists statement on the Bill observed:

'As physicians who work routinely with very vulnerable people, we find ourselves deeply concerned by the pressures that legalisation of PAS could impose upon our patients'.¹¹⁵

The Bill would, moreover, prove but a first step toward euthanasia, both voluntary and non-voluntary, and in an ever-widening range of cases. As the Royal College asked:

'Why limit PAS just to the dying? Why limit to those with life threatening illness? Why limit to people with mental capacity?'¹¹⁶

It will be recalled that Lord Joffe has candidly admitted he would like the Bill to be of 'much wider application'.¹¹⁷ If it is enacted, it surely will be. And as the experience from abroad suggests, he would not have very long to wait.

¹¹⁴ The imbalance in evidence about practice overseas evident in volumes I and II is also apparent in volume III (which contains a selection of written submissions by individuals). Volume III contains four Dutch/Belgian-based submissions in favour of euthanasia (pp6; 36; 54; 59) and only one against (p111). Similarly, it contains two US submissions in favour of PAS (pp1;80) and none against. The three Oregon doctors who gave oral evidence against the Oregon law (II, p329ff) also made a written submission (personal communication, Dr William Toffler, 7th November 2005). It appears in neither volume II nor III.

¹¹⁵ Op cit n92, supra, 2.5.

¹¹⁶ Ibid. The founder of 'Dignitas', the Swiss assisted suicide organisation, recently commented that the requirement of a terminal illness is a 'British obsession', adding: "We never say no. Even those suffering from Alzheimer's will have lucid moments in which they may choose to die once a certain point has been reached, such as when they can no longer recognise their children." *The Sunday Times*, 16th April 2006. As we have seen, the Royal College has expressed itself 'deeply worried' by the Bill. For other expert bodies, such as the World Medical Association, which have considered and rejected the arguments for legalisation see Keown, chs 16-18.

¹¹⁷ II, 3 (i)

Glossary

Physician-assisted suicide (PAS): suicide committed with the intentional assistance of a physician (as where the physician provides the patient with a prescription for lethal drugs in order to assist the patient to commit suicide).

Voluntary Active Euthanasia (VAE): the intentional termination of a patient's life by an act (as by the injection of a lethal drug) at the request of the patient, because the physician believes death will benefit the patient.

Non-Voluntary Active Euthanasia (NVAE): the intentional termination of the life of a patient who is unable to request it, such as a baby or an elderly person with advanced dementia, because the physician believes that death will benefit the patient.

Involuntary Active Euthanasia (IAE): the intentional termination of the life of a patient who is capable of requesting euthanasia it but does not want it, because the physician believes that death will benefit the patient.

(Note: 'euthanasia' in all its forms involves the *intentional* (purposeful) termination of a patient's life. It is to be distinguished, as it has long been in the criminal law and in the ethics of the medical profession, from administering palliative drugs with the intention of easing a dying patient's suffering where the doctor *merely foresees* that the drugs may or will, as a side-effect, hasten death.)

The Assisted Dying for the Terminally Ill Bill (ADTI): a private member's Bill introduced into the House of Lords in November 2005 by Lord Joffe, which would permit physician-assisted suicide in certain circumstances.

The Report of the Select Committee on the Assisted Dying for the Terminally Ill Bill (ADTI Report): the Report (published in April 2005) of a House of Lords Select Committee appointed to report on the issues raised by a similar Bill previously introduced by Lord Joffe.

The Death with Dignity Act (DWDA): a statute in the US state of Oregon which permits physician-assisted suicide and which came into force in 1997.

Oregon Department of Human Services (ODHS): Oregon's agency for health and human services, the body which doctors who write lethal prescriptions under the Death with Dignity Act are supposed to notify.

Oregon Board of Medical Examiners (OBME): the regulatory body for the Oregon medical profession.

OMA: Oregon Medical Association

BMA: British Medical Association

NCHSPCS: National Council for Hospice and Specialist Palliative Care Services

Some suggested websites and books

<http://www.publications.parliament.uk/pa/ld/ldasdy.htm>

<http://www.publications.parliament.uk/pa/ld200506/ldbills/036/06036.i.html>

<http://www.oregon.gov/DHS/ph/pas/>

<http://kennedyinstitute.georgetown.edu/index.htm>

<http://www.iaetf.org>

<http://www.pcccf.org>

<http://www.linacre.org>

Carlos Gomez, *Regulating Death: Euthanasia and the Case of the Netherlands* (Free Press, 1991)

Luke Gormally (ed), *Euthanasia, Clinical Practice and the Law* (Linacre Centre, 1994)

John Keown, *Euthanasia Examined* (Cambridge University Press, 1995)

Herbert Hendin, *Seduced by Death: Doctors, Patients and the Dutch Cure* (Norton, 1997)

Kathleen Foley and Herbert Hendin, *The Case against Assisted Suicide: For the Right to End-of-Life Care* (Johns Hopkins University Press, 2002)

John Keown, *Euthanasia, Ethics and Public Policy* (Cambridge University Press, 2002)

Neil Gorsuch, *The Future of Assisted Suicide and Euthanasia* (Princeton University Press, forthcoming)

'The debate on euthanasia has been in real need of a work of this quality. The combination of deep learning and the highest intellectual discipline make this an indispensable source for all. The reader will become factually enlightened and ethically enriched. And the debate should move to a level of serious enquiry which is essential if principle is to be protected against expediency.'

Lord Brennan

About the Author



Professor John Keown graduated in law from the University of Cambridge before taking a doctorate at the University of Oxford. After being called to the Bar he lectured in the law and ethics of medicine at the University of Leicester and then at the University of Cambridge, where he was a Fellow of Queens'

College and of Churchill College.

In 2003 he was elected to the Rose F Kennedy Chair of Christian Ethics in the Kennedy Institute of Ethics at Georgetown University. His other publications (which have been cited by bodies including the US Supreme Court and the House of Lords) include *Abortion, Doctors and the Law* (1988), *Euthanasia Examined* (1995) and *Euthanasia, Ethics and Public Policy* (2002), all published by Cambridge University Press.