

VES

choice, dignity.

The Quality of Mercy

A report into assisted dying
and mercy killing in the UK

Second Edition
1 February 2004

Foreword

Following Diane Pretty's death in 2002, and Reginald Crew's decision to go to Dignitas in Zurich for an assisted suicide in 2003, assisted dying has become a hotly debated issue in the Press and in Parliament. There have been almost 2,000 articles written on the issue since the beginning of 2003, and the Second Reading debate of the Patient (Assisted Dying) Bill was one of the best attended in recent times. However, the debate consists mainly of assumptions, and usually takes place in a vacuum without any reference to what really happens at the end of life. This report aims to anchor the debate in the most up-to-date evidence available in the UK.

This is the first time VES has brought together all the evidence and research which is available to us in relation to end-of-life decisions. In addition, new research has been carried out into what really happens following such decisions: the 'botched' suicides and the emotional trauma suffered by many mercy killers who help a loved one to die. What the report shows is that the current options at the end of all our lives are far from adequate. Many of us will die in pain, without the dignity we hoped for. The current law on assisted dying is failing all of us: patients, doctors and the vulnerable. In line with recent proposals from the Council of Europe and European Parliament, we believe that the Government must commission comprehensive research into end-of-life decision-making in the UK in order to identify the most effective way of correcting this failing.

The Voluntary Euthanasia Society (VES) is the leading research organisation in the UK on legal and human rights issues relating to end-of-life decision-making. VES advised the European Court of Human Rights in the Diane Pretty case on the comparative legal position on assisted dying throughout Europe, and has been closely involved most recently with Lord Joffe in connection with the Patient (Assisted Dying) Bill 2003. VES is regularly consulted by Government, NHS Trusts, Citizens Advice Bureaux and doctors on end-of-life decision-making.

VES was established in 1935 by doctors and members of the clergy, and currently has over 50,000 members and supporters. Of these, a significant number are doctors and nurses or people suffering from a terminal illness. VES aims to carry out its activities within an ethical framework and with an appreciation of the sensitivities of people who are suffering unbearably from terminal illnesses.

VES believes that the wishes of the patient should be central to all medical treatment decisions. We believe that a competent adult who is suffering unbearably from a terminal illness should be able to ask for, and receive, medical help to die at their own persistent and considered request, if that is what he or she wants.

Every year we are contacted by hundreds of terminally ill people who would like the option of medical help to die if their suffering becomes unbearable. This report aims to give these people a voice by setting out why they would like to see a change in the law that gives them the option of medically assisted dying.

Acknowledgements

VES would like to thank Professor John Griffiths of Groningen University and Dr Richard Tur of Oxford University for their help and assistance in compiling this report.

We would also like to thank all those with terminal illnesses who have spoken out publicly in spite of their difficult circumstances in order that one day all of us may benefit from a safe and just legal framework governing end-of-life decision-making.

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Case study

From Mark Sanderson's book *Wrong Rooms*¹

Drew Morgan died of skin cancer in 1994, three months after he was diagnosed. Shortly after diagnosis Drew made his partner, Mark, promise that he would help him to die if things became unbearable. Drew began to bleed internally. He lost sight in one eye, suffered severe constipation, his genitals became distorted, and he lost motor control in one arm. He was in never-ending pain, despite the increase in morphine from 10mg a day to 240mg a day.

Following his discharge from hospital, Drew again raised the issue of an assisted death. He did not want his illness to dictate the timing of his death. He wanted to decide when to die. Drew was soon in so much pain, and Mark thought that it was time to carry out Drew's request. He began to smother him with a pillow.

"His hands shot up and grabbed my wrists. His strength was astonishing. I whipped the pillow away. His eyes bored into mine. Shock and terror were mixed with sheer rage. At that moment I experienced true horror for the first time. Nothing that had gone before prepared me for it ... I burst into tears." (p. 215)

It was not the right time for Drew. Drew told Mark that he would tell him when he was ready. When that time came, Mark smothered him.

"I pressed down so hard I was afraid I would break his nose. He was much weaker now but the strength of his resistance still surprised me. It was pure reflex. It had to be ... I kept the pillow there long after the bucking had stopped ... It was over." (p. 219)

In the months following Drew's death, Mark's life fell to pieces. He became reliant on alcohol and drugs, and made several attempts to take his own life. He longed to talk about what he had done but told no one. He could not live with himself. He felt guilty.

In 2002, Mark published 'Wrong Rooms', telling the story of his experience. He explains that writing the book 'set him free'. He was unable to come to terms with what he had done until he had confessed.

Home Office statistics indicate that nearly 30% of mercy killers subsequently end their own lives. Many of those who assist in the death of a terminally ill relative experience guilt, which can lead to self-mutilation, psychological problems and drug dependency.

¹ Sanderson M, (2002), *A memoir: Wrong Rooms*, Scribner: London.

I. Summary

1.1 This report demonstrates that from the evidence available the current law on assisted dying in the UK is failing. It does so by drawing upon a diverse range of data, including case studies, European law, international academic research, opinion polls, government statistics, press research and expert opinion.

1.2 The 1961 Suicide Act, which governs England and Wales, provides that a person who aids, abets, counsels or procures the suicide of another, or an attempt by another to commit suicide, shall be liable on conviction or indictment to imprisonment for a term not exceeding 14 years. Assisted dying where a person's life is ended at his own request by a third party, in order to bring to an end his unbearable suffering, can be charged as murder or manslaughter, even if the person is dying and has received assistance to die from his doctor. The penalty for murder is a life sentence.

1.3 The most important public policy reasons why the criminal law needs to be changed are as follows:

- The current law results in grievous and hopeless suffering for a significant number of people who would like to be able to have a doctor's help to die in order to bring their suffering to an end.
- Research indicates that England and Wales have the harshest law on assisted dying in Europe. Most other European countries recognise that there are occasions when people ask for help to die.
- Terminally ill people would like the choice of an assisted death. Two surveys from 2003 show that between 40% and 50% of doctors had been asked by a terminally ill patient for help to die.
- Assisted dying takes place in the UK despite being against the law. A survey in 1998 found that one in seven UK GPs admitted to helping patients to die at their request, even though this is a criminal offence.
- There is a discrepancy between what the criminal law says and how the law is applied. Relatives and doctors do help terminally ill people to die, and even though this is a criminal act liable to a potentially lengthy prison term, there are very few prosecutions each year.
- VES has found that a high proportion of those who help a loved one to die go on to self-harm, with 30% of suspects in reported cases of mercy killing committing suicide.
- The criminal law is not the appropriate way to regulate medically assisted dying for the terminally ill. It neither protects the vulnerable nor addresses the very real issue of terminally ill people wanting help to die in order to put an end to their suffering.
- Because medical assistance to die is a criminal offence, many terminally ill people choose to end their lives themselves while they are still physically able to do so. The failure by the State to provide the option for medical help to die at the end of life has the unforeseen consequence of shortening life.

- As the British Medical Association and National Council for Hospice and Palliative Care services have confirmed, palliative care does not prevent all requests for help to die. UK research has found that cancer patients receiving palliative care were twice as likely to want an assisted death as those not receiving it, even when the care was considered good or excellent.
- Despite great advances in pain control, studies have shown that some patients' pain cannot be adequately managed. However, pain is not the most important reason for requesting medical assistance to die. Loss of autonomy, the inability to participate in activities, and the loss of control over bodily functions are cited by patients as being more important reasons.
- There is overwhelming support for a change in the law. Over 80% of the UK public believe that a person who is suffering unbearably from a terminal illness should be allowed by law to receive medical help to die. A recent survey of the medical profession found that 55% thought that medical help to die should be permitted when a patient has a terminal illness and uncontrollable suffering.
- The Netherlands and Oregon both demonstrate that it is possible to have in place a system whereby terminally ill patients can ask for medical help to die within a strict system of safeguards. Research from these countries has shown that, with this system of regulation, there comes better communication between doctor and patient, and better protection for the vulnerable. Contrary to claims, there is no evidence of a 'slippery slope'.

2. Definitions

Assisted dying

Defined as: 'the attending physician, at the patient's request, either providing the patient with the means to end his life or ending the patient's life'. The term is more comprehensible than other terms such as voluntary euthanasia (VE) or physician-assisted suicide (PAS), which have been commonly used by others. VE is especially imprecise, having acquired a looseness of meaning.

Double effect

The administration of painkillers or sedative drugs necessary for the relief of a patient's pain or severe distress, in the knowledge that a probable consequence is the shortening of the patient's life.

Mercy killing

The ending of the life of a person who is suffering unbearably from an illness by someone who is not a medical professional, on compassionate grounds, with or without the explicit request of the person who dies.

Non-voluntary euthanasia

Ending the life of a person who does not have the capacity to take informed decisions and, therefore, cannot make a request.

Physician-assisted suicide (PAS)

Where the doctor prescribes a lethal dose of a drug for the patient to take at a time of his choosing.

Terminal illness

An incurable and physical illness which is likely to result in death within six months. This is the medical definition of this term; it is narrower than the lay definition.

Unbearable suffering

Suffering by reason of pain or otherwise which results from the terminal illness, and which the patient cannot tolerate.

3. Assisted dying in Europe and Oregon: the legal position

3.1 Research indicates that England and Wales have the most inflexible and restrictive laws on assisted dying in Europe. The 1961 Suicide Act, which governs England and Wales, provides that a person who aids, abets, counsels or procures the suicide of another, even if that person is terminally ill, or an attempt by another to commit suicide, shall be liable on conviction or indictment to imprisonment for a term not exceeding 14 years. Assisted dying where a person's life is ended at his own request, in order to bring to an end unbearable suffering, can be charged as murder or manslaughter, even if the person is dying and has received assistance to die from their doctor. The penalty for murder is a life sentence.

3.2 John Griffiths, Professor of the Sociology of Law at Groningen University, states that there is a widespread assumption that the criminal law is 'the ultimate' remedy, not only in the sense of being the last resort, but also in the sense of being really effective [1]. It is this unchallenged assumption that currently stands in the way of serious thought about the problem of end-of-life decision-making. Since medical practice and the criminal law do not dovetail or interface practically, another framework needs to be devised, as in Oregon, Belgium or the Netherlands, to regulate the practice of doctors helping their patients to die, which will continue in any event.

3.3 A VES submission to the European Court of Human Rights (2002), and a survey conducted for the Council of Europe (2003)², which researched the laws relating to assisted dying in England and Wales by comparison with other European countries, found that:

(i) In England and Wales (unlike countries such as Portugal, Italy, Belgium, Poland, Austria, Denmark, Spain, Norway and the Netherlands), the law makes no distinction between the ending of someone's life, who has asked for help to die, and other cases where no such request has been made.

(ii) Assisting a suicide is not a crime in countries as diverse as Sweden, Finland, Switzerland, Belgium, the Netherlands, Germany and France.

(iii) In the Netherlands, Belgium and Switzerland, the State permits doctors to help their patients to die; and in the Netherlands and Belgium the right of terminally ill people to be able to ask for medical help to die is underpinned by rigorous legislation.

2 Can be found at http://www.coe.int/T/E/Legal_Affairs/Legal_co-operation/Bioethics/Activities/Euthanasia/
For a summary of the report, see 'Euthanasia-assisted suicide across Europe', *Bulletin of Medical Ethics*, Dec-Jan 2003, Vol. 184, p. 4-5.

3.4 Outside Europe, Oregon in the US legalised physician-assisted suicide in 1997. It arose following a citizen's initiative, which was passed in November 1994. The proposal was to let terminally ill Oregon residents use a prescription for life-ending medication which had been prescribed by a doctor. The medication would be self-administered by the patient without the doctor being present. The ending of life under the Death with Dignity Act 1997 is not legally defined as suicide. It only permits physician-assisted suicide and does not allow doctors to administer life-ending medication.

4. Terminal illness and life-ending

In October 2002, 80-year-old Sir Derek Bibby, who had been suffering from prostate cancer and leukaemia, ended his life in his sauna by pouring rat poison on the coals to produce aluminium phosphide. His daughter found a note warning her not to approach the sauna, but to call 999. Fire-fighters found him barely conscious. He was pronounced dead on arrival at Arrowse Park Hospital, Birkenhead. Due to the toxic nature of his body, a post-mortem could not be carried out, and the accident and emergency department had to be closed for 12 hours. (The Guardian, 29 November 2002)

4.1 Like many terminally ill people, Sir Derek Bibby chose an extreme method to ensure he succeeded in ending his life. This must have resulted in great distress to his family. It also resulted in a severe disruption of services, and a threat to the well-being of others through the toxic nature of the chosen method and the unavailability of accident and emergency services.

4.2 Numerous studies have documented the ending of life by terminally ill people [2]. Evidence suggests that the prevalence of physical illness in life-ending cases is between 30% and 40% [3]. VES receives in excess of 500 telephone calls a year from terminally ill people who wish to end their lives. They are not alone. At least five other well-known charities in the health sector contacted by VES also receive telephone calls from terminally ill people who wish to die. However, none of this information is formally collated, and there is a lack of data on the incidence and outcome of attempts to end life by people suffering from a terminal illness.

Mrs Curry, a GP suffering from motor neurone disease, ended her life in January 1999 by taking an overdose. She did not want to drag out this "undignified life that isn't really a life". (The Guardian, 6 December 2001)

In January 2000, Charles, 56, suffocated himself, using a plastic bag. He had MND. He was not depressed and had written letters to his family, informing them of his decision. It was clear this was a planned and rational decision to end his life. (Marlborough Gazette & Herald, 11 November 2001)

4.3 Both of these people were suffering from MND. Diane Pretty, Reginald Crew and John Close, who also went to Dignitas in Switzerland for an assisted death in 2003, all suffered from MND. MND or amyotrophic lateral sclerosis (ALS), which is the American terminology, is a terminal illness which results in the progressive loss of motor control, paralysis and respiratory failure. Research from Oregon found that in 1999, PAS accounted for 0.4% of deaths among cancer patients, but 5% of deaths in patients with ALS [4]. Similarly, 20% of ALS patients choose medical help to die in the Netherlands [5]. Compared with the estimated frequency of physician-assisted death in the Netherlands, which is 2.7% of all deaths, this figure is notably high. Perhaps these

statistics are not surprising, given that, as the House of Lords' judgement acknowledged in Diane Pretty's case:

Diane wanted to be spared the suffering and loss of dignity which is all that is left of her life for her, and would like to control when and how she dies.

4.4 An online survey of 1,000 doctors by Medix-UK in 2003³ found that 40% of doctors had been asked by a terminally ill patient for help to die. Medix-UK is an independent information service provided to doctors.

- Around 20% of doctors surveyed for the *BMA News Review* in 1996 had been asked by a terminally ill patient to end their life.⁴
- McLean [6] found that 28% of doctors had been asked to provide the means for a patient to end his or her own life.

A survey⁵ of over 2,000 doctors published in *Doctor* magazine in 1995 found that 62% of doctors had been asked by a patient to hasten their death. Ten per cent had been asked several times.

Dr Eric Rose told the BMA's annual conference, in July 2003, that long conversations with his patient John Close who was suffering from MND had made him rethink his stance on medically assisted dying. Dr Rose told doctors at the conference that John Close had told him that he "did not want to go on living like this, he had had enough ... all the professionals had a meeting and concluded that he was rational and there was nothing we could do for him to make him change his mind". Dr Rose told the conference that John Close, who went to Dignitas in Switzerland and did receive help to die, "had opened his mind to the topic" of whether patients should have the right to choose.

(The Scotsman, 4 July 2003)

- The Dutch Government has commissioned regular national surveys on assisted dying ('the Rummelink reports'), carried out in 1990, 1995 and 2001 [7,8,9]. In 2001, 9,700 concrete requests were made for an assisted death. However, only a third (3,800) of these requests were granted. In half of the cases in which a request for assisted dying was not granted, the patient died of the underlying illness before the decision as to whether to help the patient to die could be taken; and in a fifth of cases the doctor did not grant the request because not all of the criteria were met. Therefore, 2.7% of deaths in the Netherlands in 2001 were as a result of assisted dying at the request of the patient.

4.5 In the Netherlands, of those who receive assistance to die, 88% were cancer patients, 1% suffered from coronary illness, 3% from diseases of the nervous system, 2% from pulmonary disease, and 5% were not classified. In 90% of cases where medical help to die was given, it is estimated that life was shortened by one month or less, with 42% of cases involving the shortening of life by less than a week.

3 <http://www.medix-uk.com>

4 *BMA News Review*, 4 September 1996.

5 'A deadly dilemma', *Doctor*, 9 February 1995.

5. Reasons for life-ending

Jean, 59, had been suffering from cancer. In April 2000, she chose to take her life. She poisoned herself with carbon monoxide by feeding a hosepipe from the exhaust pipe through the window of her car and leaving the engine running. Her husband said, "She was in considerable pain which could not be properly controlled."

(The Birmingham Post, 13 September 2000)

5.1 Some of those against the legalisation of assisted dying maintain that good palliative care and pain control alleviate the suffering that causes requests for help to die. Palliative care is defined as non-aggressive treatment of the symptoms of terminal disease where there is no hope of a cure.

5.2 Pain cannot always be adequately controlled. Opioids can produce good pain control in 80% of patients [10], but a number of studies acknowledge that pain control for some patients remains inadequate [11,12].

5.3 However, pain is not the most important reason given by terminally ill people for wanting to end life. Evidence from Oregon consistently shows that terminally ill people ask for help to die due to loss of autonomy, the inability to participate in activities, and the loss of control over bodily functions. Pain consistently ranks fifth out of six reasons given by patients for requesting PAS. The majority of those who received assistance to die were also receiving palliative care [13,14,15,16,17].

Biz Ivor from the Orkneys, who is terminally ill with Multiple Sclerosis, said that she would continue with her plans to end her life after symptoms worsened. She was answering allegations in court following being arrested for supplying other people with debilitating diseases across the UK with cannabis. Ms Ivor said that she had always "made clear her intention to end her life as her condition declined. The plans are all made. I don't want to fight on much longer," following losing her balance, her eyesight and becoming paralysed from the chest down over the last 18 months.

(The Herald, 2 July 2003)

5.4 Research in the UK by Seale and Addington-Hall [18] has shown that even with good palliative care, some patients will still suffer unbearably from a terminal illness or a serious incurable and progressive physical illness, and may want medical help to die. The study found that cancer patients who were in hospice care were twice as likely to want help to die as those who were not receiving hospice care, even when the care received was considered good or excellent. The reason for this may be that care in hospices provides an environment where people are more willing to express their worst fears.

Requests for help to die may indicate not that patients are giving up in the face of suffering, but that they are positively asserting their desire to control events.

Seale and Addington-Hall also commented:

If the psychological roots of the desire for euthanasia lie in a desire for personal control, this may explain why good care appears to make only a small difference.

5.5 Not everyone's pain can be treated adequately. A US study of cancer patients found that 40% of patients with pain experienced poor pain control [19]. Another US study of lung cancer patients in palliative care found the prevalence of pain to be 90%. Twelve per cent of the patients were not able to achieve acceptable pain relief [20].

5.6 No amount of palliative care can address concerns regarding loss of autonomy and control over bodily functions because these are existential rather than medical concerns. This was acknowledged by the National Council for Hospice and Specialist Palliative Care Services, in 1997⁶:

... universal availability of excellent palliative care services will not and can never eliminate all such rational and persistent requests for euthanasia ... We acknowledge that maintaining a legal prohibition on the practice of euthanasia exacts a high price on some individuals who may feel that their autonomy has been unacceptably compromised.

5.7 The majority of patients who received assistance to die in Oregon were on hospice programmes. Requests for physician-assisted deaths were found to be infrequently triggered by unrelieved pain alone, but more commonly resulted from a combination of physical symptoms and debility, weakness, lack of meaning, weariness of the dying process, and reasons relating to what it is to be a human being, namely loss of autonomy, decreasing ability to enjoy life, and loss of control of bodily functions.

Shirley Nolan, founder of the Anthony Nolan Trust, and a sufferer of Parkinson's disease, chose to end her life in July 2002. She wrote:

I hope today I can end the horror my life has become ... At times I cannot even move, speak, or breathe. I am further demeaned by staggering, shaking, and falling, appearing inebriated. It is a life without quality. It is a living hell.
(The Evening Standard, 16 July 2002)

She made it very clear that she planned to take her life while she was physically able, and had previously attempted to do so unsuccessfully.

5.8 Even with comprehensive palliative care, up to 35% of patients in hospice care in Oregon described their pain as severe in the last week of life, and 25% described their shortness of breath as unbearable. In addition, on occasions, delirium, bleeding, open wounds, profound weight loss and seizures can challenge the most experienced of hospice teams. Even very good palliative care, as in the Netherlands and Oregon, cannot meet the needs of all patients, for a variety of reasons.

6. The law as it stands shortens life

6.1 Many serious physical illnesses render the person physically unable to end their life. Consequently, many choose to take their lives while they are still able to do so. They die alone, not wanting to implicate others, fearing that they may subsequently face prosecution for aiding

6 <http://www.hospice-spc-council.org.uk>

and abetting suicide. Therefore, the current law which does not allow the option of medical assistance to die in some cases shortens rather than prolongs life.

6.2 The option of a medically assisted death would prolong life.

A 74-year-old sufferer of MND ended her life. Her suicide note said, "I have never had any inclination towards suicide. However, MND is a relentless disease. If I stick it out, I could finish totally paralysed and unable to speak ... It is necessary to take action while I can still swallow ... This is the best choice..." Her children were upset that the law forced her to take her life in secrecy and alone. They strongly felt that she would have lived longer if a dignified death were available to her.

(The Guardian, 5 July 1997)

6.3 Evidence from Oregon suggests that the option of PAS prolonged the lives of those who were granted the option. Weinberg [21] suggests that patients take comfort in the knowledge that they can receive medication to end their life if they want to.

7. Availability of information on methods of self-deliverance

7.1 Based on the premise that the desire to end life is impulsive, the current National Suicide Prevention Strategy (NSPS) aims to reduce the availability of methods of self-deliverance. However, information about self-deliverance is readily available, and is used by terminally ill people who have made the well-considered decision to end their life to relieve their suffering.

A local newspaper reports how a 59-year-old woman with MS 'meticulously planned' the end of her life, following 20 years of suffering from the illness. She killed herself using a plastic bag and an overdose, and was found by her husband surrounded by books she had used to research her suicide. The coroner concluded that she had 'carefully researched taking her own life'.

(The Slough & Langley Express, 22 August 2002)

7.2 A terminally ill person who has made the decision to end their life would not have to look far for information. A quick Internet search revealed a dozen websites that give information on how to end one's life, many of which provide extensive information on a broad range of methods.

8. 'Botched' attempts to end life

8.1 Without accurate knowledge and the correct means of self-deliverance, many of these attempts to end life are unsuccessful. This can lead to serious health complications. For example, in November 2002 a UK organisation was contacted by a man with terminal cancer, wishing to end his life. The following day he attempted to kill himself by jumping from a building. The man survived, and although the consequences of his attempt are unknown, he must have sustained significant injuries⁷. An elderly lady with Parkinson's disease contacted VES to tell of the kidney failure she had suffered after an unsuccessful attempt to end her life by taking an overdose⁸. The legal option of a medically assisted death would prevent these 'botched' attempts by terminally ill people.

7 VES Communication, November 2002.

8 VES Communication, September 2001.

8.2 In 2002, Magnusson carried out research on the healthcare workers in the 'euthanasia underground' in Australia and America. Not only did he find evidence for the practice of assisted dying, with and without the request of the patient, he found that healthcare workers used a variety of methods:

Because it (assisted dying) is practised in secret there is no manual on 'how to get it right'. Interviewees earned their expertise through trial and error and ... the interviewees revealed an odd assortment of overdose recipes. Many of these had featured in 'botched attempts.' There was little consensus over which recipes were thought to be more effective in practice. (p. 145)

8.3 Magnusson points out that little is known about the prevalence of botched attempts, but found that 20% of attempts identified by the research resulted in 'botches'. This was often due to the miscalculation of the dose of drugs required. When overdose attempts failed, workers were forced to resort to strangulation or suffocation. Magnusson found that loss of dignity of the patient was a prominent feature of failed attempts, and referred to a patient who was sick following the self-administration of tablets. He subsequently died after ingesting his own vomit.

8.4 If medical assistance to die were made legal in the UK, assisted dying would be carried out by qualified doctors, who have access to, and are trained in, the use of appropriate drugs to end a patient's life.

9. Dignitas

9.1 Over the past 18 months, Dignitas, a Zurich-based organisation which provides assistance to die to foreigners, has received a great deal of media attention in the UK. There has been a considerable increase in the numbers of foreigners travelling to Switzerland because assisted dying is illegal in their own countries. In 2002, 55 foreigners did so. This compares to three in 2000⁹. In October 2002, a man with terminal throat cancer became the first UK person to receive help to die from the organisation. Dignitas has also helped Reginald Crew and John Close, both MND sufferers, to die, and in April 2003 the Press revealed that three other Britons had died at the organisation, at least two of whom were not terminally ill.

9.2 Switzerland is unusual in that it, unlike the Netherlands, Belgium and Oregon, does not have carefully drafted assisted dying legislation. People can be helped to die in Switzerland because assisted suicide, as in many other European countries, is not illegal. Dignitas will assist in the death of people without a terminal or physical illness, and would seem to offer assistance on the basis of a short consultation. As a consequence, there is a failure to consider what other alternatives, such as palliative care, may be appropriate. This is in contrast to the Netherlands, where the regulated system of medically assisted dying promotes communication between patients and doctors, and ensures assisted dying occurs only after other alternatives have been considered.

9.3 Under UK law, a person who accompanies a relative to Dignitas is likely to have committed the crime of 'aiding or abetting a suicide', which carries the penalty of up to 14 years' imprisonment. Reginald Crew travelled to Switzerland, accompanied by his wife and daughter. On their return, the CPS launched an investigation into the case to decide whether to prosecute.

9 *The Observer*, 26 January 2003.

Norman Bettison, Chief Constable of Merseyside Police, stated: "... it is necessary to understand the events surrounding Mr Crew's death. At this stage we hope to be able to carry out the inquiries without having to bother Mr Crew's wife or close family."¹⁰ In April 2003, it was announced that Mrs Crew would not be facing prosecution due to insufficient evidence, and it not being in the public interest.

9.4 Richard Tur, Benn Fellow and Senior Law Tutor at Oriel College, points out that the outcome of the Crew case:

... will open the door for anyone in a similar situation, because it will now be very difficult for any other police force to justify prosecution.¹¹

It appears that the CPS is prepared to turn a blind eye to assisted dying, providing it occurs outside the UK. Alternatively, it may be that the CPS recognises help to die at the patient's request is a humane option in certain circumstances.

9.5 VES has received hundreds of enquiries from people wanting contact details for Dignitas. Concerned that providing these details could be interpreted as assisting a suicide, VES does not disclose this information. However, this has not prevented many UK citizens from joining the organisation.

10. The incidence of assisted dying in the UK

10.1 Home Office figures reveal 38 reported cases¹² of mercy killing in the period 1990–2002. In addition, 38 cases of aiding and abetting a suicide were presented at magistrates' courts in the period 1990–2001. However, these figures are the tip of the iceberg. They represent reported cases only, and underestimate the true level of assisted dying, whether the assistance was provided by doctors or relatives and friends, occurring in the UK.

10.2 Formal research has not been carried out in the UK, so the true level of assisted dying is not known, despite repeated requests by VES to the Government for this research to be carried out. However, the available evidence shows that, despite it being a criminal offence, some doctors in the UK do help their terminally ill patients, who are suffering unbearably, to die at their request.

- In a 1994 survey of doctors, 12% admitted to having taken active steps to end a patient's life [23].
- A 1996 postal survey of 1,000 UK medical practitioners found that 12% knew a colleague had assisted a patient to die, and 4% claimed that they had provided a patient with the means to end their life [6].
- A 1997 survey¹³ of GPs found that 47% had eased a patient's death.
- A survey¹⁴ by the *Sunday Times* in 1998 found that one in seven UK GPs admitted to helping patients to die at their request.

10 *Evening Gazette* (Teesside), 24 January 2003.

11 *Daily Post* (Liverpool), 10 April 2003.

12 This figure refers to cases where the person who died was over 18 years of age.

13 *Pulse*, Vol. 57. 1997.

14 *Sunday Times*, 15 November 1998.

- In 2003, a survey of more than 1,173 nurses for the *Nursing Times*¹⁵ indicated that at least one in 20 believed that colleagues are helping terminally ill patients to die.
- In Australia [24] and Belgium [25], academic research indicated that 1.8% and 1.3% respectively of deaths are a result of physician-assisted dying.

10.3 The doctors' survey carried out by Medix-UK in 2003 (see 4.4) asked for doctors' opinions in relation to a number of different scenarios, referring to patients in different circumstances. When asked the question in this manner, 55% of doctors thought that physician-assisted suicide should be permitted for patients with a terminal illness who are experiencing uncontrollable suffering.

10.4 A survey by Ward and Tate in 1994 [23] found that 46% of doctors would consider taking active steps to bring about the death of a patient if it were legal to do so, and a survey¹⁶ published in *Doctor* magazine in 1995 found that 43% of doctors said that they would practise it if it were legal.

11. Death by double effect: a 'good' death?

11.1 'Double Effect' is a principle established by Lord Devlin to the effect that although the doctor did an act which 'played some part in' the death of the patient, the doctor should not be liable, unless he intended to bring about the death. If the doctor's primary intention was to relieve the patient's pain and not to hasten death, then the doctor can take advantage of the 'double effect' principle. Notwithstanding the limit of the principle, in 1997 a BBC survey found that of the 250 doctors surveyed, 34% of doctors had used painkillers to hasten death. However, research indicates that death brought about in this way, as opposed to using appropriate drugs as in cases of assisted dying in the Netherlands, can be distressing and undignified.

11.2 A number of opioid analgesics are used to treat pain. Morphine is the drug of choice for the management of cancer pain because it is effective, easy to administer, and relatively inexpensive. However, high doses of morphine can cause what has been termed 'paradoxical pain', where the drug increases the intensity of pain, a consequence of abnormal metabolism of the drug [26,27].

11.3 Morphine is also associated with a number of side effects including nausea and vomiting, constipation, sedation, xerostomia (dryness of mouth which can cause discomfort, impaired swallowing and speaking, and loss of taste), sweating, intolerable itching, inability to urinate, abdominal pain, blurred vision, and involuntary muscle spasms. The patient may experience cognitive failure or delirium, and hallucinations. This is distressing for the patient and their family, and is often managed with sedation, which reduces (Maddocks et al, 1996) 'the capacity for patient participation in important human exchanges' [28]. The most serious side effect of opioid use is respiratory depression, which is the cause of death from opioid overdose in most cases [29]. Els Borst, a doctor and former Minister of Health in The Netherlands, has stated that death by 'double effect' can be a bad death, and believes that more appropriate medication should be used at the patient's request to secure death¹⁷.

15 *Nursing Times* survey, (2003), 'Dying Wishes: Should patients have the right to choose when and how they die?' *Nursing Times*, 99 (47), p. 20–22.

16 See footnote 5, p. 9.

17 *VES Communication* the Netherlands, 17 February 2003.

11.4 Concern was also raised by Lord Lester in the recent House of Lords debate on the Patient (Assisted Dying) Bill 2003 as to whether the principle of ‘double effect’ works under criminal law:

The problem with the existing state of the law is for the doctor to know what can lawfully be done to relieve suffering towards the end of a patient’s life without fear of prosecution. One difficult problem concerns the relationship between intention and foresight in deciding whether a doctor has a criminal intent. In deciding whether there is the mental element necessary for murder, foresight of the consequences is evidence of the existence of a criminal intent. The greater the probability of death as a consequence, the more likely it is that it will be treated as having been foreseen, and the greater the probability that it will be treated as having been intended.¹⁸

11.5 Terminal sedation, which means sedation with high doses of sedatives to relieve physical distress in patients close to death, with the explicit decision to render the patient unconscious, is also part of palliative care. Any life-prolonging interventions, including artificial hydration and nutrition, ventilation and antibiotics, are usually withdrawn or not initiated when death is imminent, to ensure that the process of dying is not prolonged. Like ‘double effect’, it is deemed ethical because although death is foreseen, it is not intended.

11.6 There are no figures in the UK as to how many deaths each year are as a result of ‘double effect’ or terminal sedation, or indeed whether the patient asked to be allowed to die in this way. It is likely that in the majority of cases, there was no such request by the patient, for the simple reason that if such a request was made and the doctor acted on it, then the intention of the doctor would not be pain relief but the ending of life, which is unlawful. This explains the surprise of so many relatives when the patient dies. They had not been made aware that the medication being given to the patient could lead to the patient’s death.

11.7 A recent study published in the *British Medical Journal* [30] assessed the effect of assisted dying on bereaved family and friends. The survey, which took place in the Netherlands, found that the bereaved family and friends of cancer patients who asked for and received medical help to die coped better with respect to grief symptoms and post-traumatic stress reactions than the bereaved of comparable cancer patients who died a natural death. While it ought never be concern for the relatives’ emotions which makes a patient ask for medical help to die, the authors conclude that the openness which characterises the care of patients who choose the time and manner of their death could benefit all who are terminally ill. Again, this underlines how important it is for doctors to recognise the dying process, and communicate fully and openly with the patient and the family.

11.8 The principle of ‘double effect’ actually prevents patients from having control over how and when they die, and leaves control of end-of-life decision-making firmly with the doctor. With patient choice very much at the centre of NHS strategy, it is time the principle of ‘double effect’ was revised to ensure that there can be full and frank discussion between doctor and patient, so that ultimately decision-making rests with the patient and not the doctor.

18 Column 1596, Official Report of the House of Lords (*Hansard*), Vol. 648, No. 103, Friday 6 June 2003.

12. Mercy killing

Janet Pitman, 75, had severe arthritis. Despite pain control, she was suffering significant pain, and begged her son to help her end her life. Peter Pitman considered ending his own life rather than carry out her wishes. She had previously attempted to end her life on a railway track, and threatened to do so again if he did not help her. In 1997, he held a rifle to her head. She pulled the trigger. Initially charged with murder, he was charged with aiding and abetting a suicide and given a nine-month sentence suspended for two years.

(Western Daily Press, 17 July 1998)

12.1 Due to the illegality of assisted dying in the UK, there is often a lack of communication between doctors and their patients regarding end-of-life options. Although some patients do ask their doctors for assistance to die, many are too apprehensive to approach their doctor, and are forced to seek reassurance from friends and families that they will assist them to end their life if the suffering becomes unbearable. They lack medical knowledge and access to appropriate drugs, and so attempts to end life may go horribly wrong, or patients may be forced to use unpleasant and extreme methods. Relatives also lay themselves open to prosecution. VES does not suggest that relatives should be able to help loved ones to die. Far from it. However, we believe legalising medically assisted dying would mean terminally ill people would not have to rely on assistance from friends and family, thereby preventing many mercy killings.

12.2 Many do feel compelled to assist terminally ill relatives to die, with or without their request, due to what they perceive as unbearable suffering. However, most of these cases are never reported, or remain a secret for many years.

In December 2000, Jon Elliot confessed on live radio to the mercy killing of his mother by morphine overdose some four years earlier. She had been suffering from cancer, weighed only four stone, was incontinent, blind, and barely able to speak or eat. Mrs Elliot's body was exhumed for investigation. However, the CPS decided to take no further action due to insufficient evidence, and charges against Mr Elliot were dropped.

(Sheffield Star, 1 December 2000)

Following the 'Eastenders' episode in which Dorothy helped Ethel to die, Eugene Cooper, 30, confessed that, seven years earlier, he had helped his friend Johnathon (Ben) Shaw to die. Johnathon, aged 27, had been suffering unbearably from AIDS.

(Worcester Evening News, 23 September 2000)

When Jaap Brown, 68, was diagnosed with MS, he said he would end his life when the suffering became too bad, and read a 'how-to' manual. When his suffering became unbearable, he took an overdose and placed a plastic bag over his head, assisted by his wife. Following the incident, Mrs Brown lied to police, and the incident remained a secret until she confessed seven years later. No charges were brought against her.

(News of the World, 29 June 1997)

12.3 Home Office statistics indicate that nearly 30% of mercy killers subsequently end their own lives. Many of those who assist in the death of a terminally ill relative experience guilt, which can lead to self-mutilation, psychological problems and drug dependency.

In July 1996, Mr David Hainsworth attempted to smother his 82-year-old father, who was suffering from cancer. However, he survived and died a week later for reasons unconnected with the assault. David suffered considerable guilt as a result of his actions and punished himself by cutting off one of his testicles. He was charged with manslaughter and put on probation for two years on the condition that he sought medical advice and counselling. (Aberdeen Press and Journal, 7 June 1997)

In 1978, Douglas Graham killed his 75-year-old father, who was suffering from terminal heart disease. The cause of the death was thought to be a heart attack, and the incident remained a secret for fourteen years during which time Mr Graham was 'tormented with guilt'. The guilt he experienced led to a suicide attempt in 1992. He confessed his crime to the policeman who found him unconscious in a car, within which he was attempting to gas himself with exhaust fumes. The judge described the crime as an exceptional case and added, "I accept that you have been tormented for 14 years now by remorse and guilt and this drove you to attempt to take your own life". He was charged with manslaughter on the grounds of diminished responsibility and sentenced to three years probation on the condition that he underwent psychiatric care. (The Daily Telegraph, 16 January 1993 and The Journal, 16 January 1993)

12.4 These case studies emphasise the consequences of carrying out a mercy killing, and being unable to talk about one's actions. Mark Sanderson, who assisted his partner to die at his request (see p. 4), suffered psychologically as a result of his actions. The law does not always stop people from helping loved ones to die. What it does do is lead to untold misery and self-harm in those who do, illegally, help a loved one to die. A law which allows terminally ill people medical assistance to die would prevent families from being forced into this situation, with the associated negative consequences.

13. What the law says and what the law does

13.1 Dr Michael Wilks, Chairman of the British Medical Association Ethics Committee, speaking in his personal capacity at the Disability Rights Commission debate on 20 January 2003, stated:

The Diane Pretty case was one of many in which a patient facing certain and distressing death requested the means to decide on the time and manner of her death, in this case immunity from prosecution for her husband if he assisted her suicide ...

We speak increasingly of the importance of patient autonomy (literally, 'self rule') in decision-making ... Increasingly, in my judgement, society expects this principle to extend to decisions similar to the case of Diane Pretty. We must emphasise at this point that the essential conditions in which such autonomy can be exercised are that the patient faces inevitable death as a result of his or her condition, and that there is full capacity to take informed decisions.

A striking feature of the Diane Pretty case, common to almost all court decisions in cases of assisted suicide in the circumstances I have just described, is that the courts do everything they can to avoid punishment. Who can doubt that, if Mr Pretty had helped his wife to die, been arrested, charged and tried, that the outcome would have been at most a suspended sentence? This anomaly in the way in which the courts deal with what is a major crime, punishable by up to 14 years in prison, can be viewed in two ways. Either that it is important that assisted suicide has a suitable deterrent sentence attached to protect the vulnerable, or that the difference

between what the law says and what the courts do adds an additional burden to the many already suffered by people such as the Prettys. I incline towards the latter view.

A further point is that, of course, autonomy is already granted by the law in some areas where non-treatment can lead to death. It occurs in the ability, protected by law, for patients to refuse life-prolonging medical treatment, even when such an informed refusal will result in death. This was apparent in the case of Miss 'B', who made the competent decision to refuse further ventilation. It is notable that in her case, the court not only upheld her right to make such a decision, but awarded damages against her doctors for a 'trespass' in refusing to respect her wishes. So the law is very clear in protecting this right. If such a decision by a patient for non-treatment, with the absolute certainty of death, can be respected, why then can we not respect a request from a patient to actively provide that death? The answer – that the criminal law says we can't – is inadequate, as it simply produces a circular debate.

My personal preference would be that it should no longer be an offence to assist the suicide of a competent individual, with a fatal or terminal condition, who requests such assistance ... We should examine existing legislation – in the Netherlands, Oregon and Switzerland, and now also in Belgium – to see how the balances in interests have been solved, or not solved.

13.2 Appendix 1 details Home Office figures on reported cases of aiding and abetting a suicide in the UK. Figures indicate that between 1990 and 2001, 22 people were found guilty of aiding and abetting a suicide, i.e. two a year (some proceedings are still pending). A third (seven) of these were placed in immediate custody. However, most did not receive a prison term. Rather, 10 received a community sentence, three received a conditional discharge, and two received a fully-suspended sentence. Information regarding length of sentences was unavailable. However, research into Press reports of aiding and abetting suicide cases, found that of nine cases identified, two-thirds of the people concerned (six) were put on probation and a third (three) received a suspended sentence. The lengths of these sentences were one or two years. Those convicted of aiding and abetting suicide have received sentences very considerably less than the 14-year prison term prescribed by law.

13.3 There is a discrepancy between what the criminal law states and how it is applied. Home Office figures on reported mercy killing cases can be found in Appendix 2. These also show that the sentencing for these cases is less than is threatened by UK law. The punishment for murder is life imprisonment. However, a defendant who has caused a person's death may be able to avoid the conviction of murder if he falls within the scope of the special defences to murder, which include diminished responsibility (dealt with under section 2 of the Homicide Act) and the pursuit of a suicide pact (dealt with under section 4 of the Act). If the plea is successful, liability is reduced to manslaughter, for which the sentence is discretionary.

13.4 In the period 1990 to 2002, there were 17 cases of mercy killing where a manslaughter conviction ensued, and length of sentencing ranged from 9 months to 36 months. Twelve of these were dealt with under section 2 of the Homicide Act, and were therefore reduced to manslaughter on the grounds of diminished responsibility, and one was dealt with under section 4, indicating a suicide pact. The remaining four were dealt with under common law.

14. Director of Public Prosecutions (DPP) decline prosecution

14.1 Home Office statistics also indicate that sometimes charges are not brought or are dropped. In 13% (five) of the mercy killing cases, and 16% (six) of aiding and abetting suicide cases,

proceedings were not initiated or were dropped on the advice of the DPP. It is clear that the DPP has exercised discretion in many cases, but it is unknown what criteria it has used when making its decisions.

In November 1993, a woman died from terminal cancer. A post-mortem revealed that she had died from acute morphine poisoning, and her husband was arrested for her murder. However, after a six-month investigation, the CPS decided not to charge him, despite 'having sufficient evidence to do so', because 'in the tragic circumstances of this case, the public interest does not call for a prosecution'.

(The Observer, 4 December, 1994)

The CPS decided not to prosecute a man who gave his mother, suffering from cancer, an overdose of morphine to end her suffering, due to 'insufficient evidence'. Following a four-month investigation it was announced: 'The CPS have taken the view there is no medical evidence to suggest what Mr Rowbottom did contributed to his mother's death.'

(The Daily Telegraph, 24 August, 1996)

14.2 It is not clear on what grounds the DPP has concluded it is not in the public interest to prosecute. This means there is a lack of clarity as to the criteria the State will apply when deciding whether it is appropriate to prosecute in a case of assisted dying. This lack of clarity leaves the most vulnerable in our society unprotected. The expectation that many more British terminally ill people will travel to Dignitas for an assisted death, makes this essential. Under current law, it is unclear whether a British citizen has committed an offence if they assist someone to die within a jurisdiction in which the act is legal. VES has repeatedly written to the DPP, asking for clarification of the criteria it uses when it decides whether to bring a prosecution in these cases. To date, the DPP have failed to disclose the criteria it uses.

14.3 While the mercy killer is often motivated by compassion, it is a matter of public concern that the absence of a law which would allow terminally ill people to ask for and receive medical help to die leaves the courts having to tackle mercy killings without an adequate frame of reference. This results in a lack of public control regarding assisted dying, and consequently leaves the vulnerable unprotected.

14.4 Far better would be a transparent legal system which would enable terminally ill people to be able to ask for medical help to die, within strict safeguards so that any instance of assisted dying outside the legislation would be far more rigorously scrutinised, and the criminal law applied consistently and appropriately. In this way, the most vulnerable members of society would be protected, while at the same time terminally ill people would be able to ask for and receive medical help to die if that is what they want at the end of life.

15. Support for a change in the law

15.1 Opinion polls and surveys consistently show that the majority of the British public support a change in the law. The latest opinion poll shows that 81% of Britons would like to see assisted dying legalised in the UK.

15.2 Research also shows that there is a high level of support for a change in the law within the medical profession.

- A survey in 1996 of 1,000 UK doctors found that 55% of general practitioners believed doctors should be allowed by law to assist in the suicide of a patient if the patient has a terminal condition, and 54% favoured a change in the law to allow physician-assisted suicide [6].

- An online survey of 1,000 doctors conducted in 2003 by Medix-UK¹⁹ found that 55% of doctors thought that physician-assisted suicide should be permitted for people with terminal illnesses and uncontrollable physical suffering. The survey also found that 40% of doctors had been asked to help a patient to die.
- A survey by Opinion Research Business in 2003 for Right to Life found that 50% of doctors had been asked by patients to assist in their death.
- In May 2003, the Department of Health received declarations signed by 1,000 senior GP partners in the South East of England in support of a change in the law to allow doctors to help their patients to die.
- A study of more than 1,173 nurses conducted in 2003 by *The Nursing Times*²⁰ found that 59% thought that the UK law should be changed to allow health professionals to help the terminally ill to end their lives.

16. The case for regulation

16.1 Research shows that in countries where a proper regulated system is lacking, non-voluntary euthanasia (doctors ending life without the request of the patient) is five times higher than in countries which do provide for a system of assisted dying. Research in Belgium [25], prior to the legalisation of assisted dying, and Australia, where it remains illegal [24], found that doctors administered lethal drugs without the patient's request in 3.2% and 3.5% of deaths respectively. However, in the Netherlands, where assisted dying is regulated, only 0.8% of deaths in 1990 [7] and 0.7% in 1995 and in 2001 [8] were cases of non-voluntary euthanasia. The comparative findings in these countries were published in *The Lancet* and are shown in **Table 1**.

16.2 Legalising assisted dying, and thereby increasing transparency and regulation, has served to protect vulnerable people from having their lives ended without their request. There has been no comparable research in the UK. We have no idea how many patients are having their lives ended with or without their consent. On the basis of the research conducted by Kuhse et al [24] and Deliens et al [25], it is estimated that 7,500²¹ people may be assisted to die at their request. However, 18,000²² people may be eased towards death without their consent.

19 See footnote 3, p. 9.

20 See footnote 16, p. 15.

21 The research in Australia by Kuhse et al (1997) estimated that 1.7% of deaths were a result of voluntary euthanasia. The research in Belgium by Deliens et al (2000) reported a figure of 1.3%. Taking the mid-point between these values, it could be that 1.4% of deaths in the UK are a result of voluntary euthanasia. 1.4% of the 530,300 deaths in England and Wales in 2001 (Office for National Statistics) equals 7,424 deaths.

22 The Australian study (Kuhse et al, 1997) estimated that 3.5% of deaths were a result of non-voluntary euthanasia. The Belgian study (Deliens et al, 2000) found this figure to be 3.2%. Taking the mid-point between these two values, it could be that 3.4% of deaths in the UK are a result of non-voluntary euthanasia. 3.4% of the 530,300 deaths in England and Wales in 2001 (Office for National Statistics) equals 18,030 deaths.

Table 1: Estimated rate of end-of-life decisions in medical practice

	Netherlands 1995	Netherlands 2001	Australia 1995	Flanders 1998
All deaths	135,546	140,000	125,771	56,354
Administration, prescription or supply of drugs with the explicit intention of shortening patient life				
Euthanasia	2.4%	2.5%	1.7%	1.1%
Physician-assisted suicide	0.3%	0.2%	0.1%	0.2%
Ending of life without the patient's explicit request, i.e. non-voluntary euthanasia				
	0.7%	0.7%	3.5%	3.2%
Total	3.3%	3.3%	5.3%	4.5%

Source: Deliens et al [25]

16.3 A recent survey of medical decisions at the end of life made by New Zealand general practitioners, published in the *BMJ* in July 2003, found that in 5.6% of cases, death was consistent with assisted dying. In 87% of cases, palliative care services were available, so it was not a lack of palliative care which led to the patient being helped to die. In 2.4% of cases, there was no discussion with the patient. This latest research is consistent with the comparative findings in Table 1, which shows that where medical help to die is an option within a carefully framed piece of legislation, the level of non-voluntary euthanasia is much lower than in countries like New Zealand, where there is no such legislation.

17. The Dutch experience

17.1 Assisted dying occurs despite being against the law, but is practised covertly, is unscrutinized, and remains unreported. One of the reasons leading to a change in the law in the Netherlands was the recognition that doctors would not report assisted dying if it were a criminal offence. The Criminal Code was amended to include special ground for exemption from criminal liability for terminating life on the patient's request providing that 'due care' criteria had been followed, and the death was reported as of non-natural causes. They recognised that the practice could not be regulated without a system of reporting.

17.2 The Dutch Government commissioned a series of studies ('the Rummelink reports') to investigate medical behaviour at the end of a patient's life. In 1990, 18% of euthanasia cases were reported, and in 1995, this figure was 41% [31]. The third Rummelink report [32] has been published recently, and shows that the reporting rate has risen to 54%²³. Those against euthanasia cite these figures as a cause for concern, stating there are still hundreds of cases that go

23 Contact NVVE (The Dutch Society for Voluntary End of Life) for more details.

unreported. This may be so. However, Professor John Griffiths of Groningen University in the Netherlands, describes the Dutch situation as a glass which is half-full, where half of the cases are being reported, a situation which is constantly improving. He points out that in countries like the UK, where there is no assisted dying law, there is no reporting, but this does not mean assisted dying is not going on. In the UK, the level of reporting is zero, and therefore, there is no provision for scrutiny or regulation.

17.3 The regulated, decriminalised nature of assisted death in the Netherlands promotes in-depth discussion about the patient's wishes, which serves to improve the doctor-patient relationship, and ensures that all palliative care and treatment alternatives have been considered. None of the Dutch commentators have found any worsening of the relationship between doctor and patient as a result of the legislation or the practice of assisted dying, which predates the legislation by many years. In 2001, the Dutch Marketing Research Institute carried out a survey and found that 85% of Dutch people supported the law on assisted dying. Only 8% did not support the law, and 7% were undecided. Far from causing distrust amongst patients, the legalisation of assisted dying in the Netherlands promotes communication between doctors and their patients.

Henk Landa has incurable throat cancer, and is being treated at Rijnstate Hospital, Arnhem. He is terrified that he might suffocate to death. He informs his doctor, Dr Douma, that he would like an assisted death at a time of his choosing as he "would like to die in a dignified manner, not in misery ...". Dr Douma embarks on a series of discussions with Mr Landa. He wants to fully understand the reasons behind the request. Only when he is satisfied that an assisted death is right for this patient does he agree with the request. Dr Douma clearly gives the case a great deal of consideration. He says, "I often think, is this right? ... Even if everything tells you it is right ... the act ... weighs very heavily on you. It's something you would like to avoid ... and is emotionally hard to cope with." Mr Landa is visited by a consulting physician who is satisfied the decision has been 'formulated gradually' and discussed with many people. Mr Landa's request for an assisted death is approved, and the hospital board is notified. On 25th June, Mr Landa dies in the presence of his family. The committee assessing the case unanimously agree that all requirements were met and that the doctor acted with diligence and care.

(*'Dying with dignity: Experiences in the Netherlands'*, a film by Rob Hoff)

17.4 Contrary to the claims of opponents of the Dutch system, doctors do not take the decision lightly. Rather, they consider the case carefully, and place the request for an assisted death and the patient's 'unbearable suffering' in the context of the life of the patient. Further, a transparent and open system of medically assisted dying lends greater support and protection to both the patient and the doctor. The success of the system has been strengthened by support from the Royal Dutch Medical Association (KNMG), to which most Dutch doctors belong, who first, in 1984, formulated 'due care' criteria – guidelines which doctors should follow to avoid prosecution. The KNMG have established the SCEN (Support and Consultation on Euthanasia in the Netherlands) system to promote careful decision-making about assisted dying, and to bring the consultation process to an outstanding level through training consulting doctors to provide expert advice. It is proving a highly successful project. By comparison, the British Medical Association and General Medical Council turn a blind eye to assisted dying in the UK. Consequently, doctors lack support, are fearful of helping their patients to die because of fear of prosecution, and yet do so without any form of regulation or control.

17.5 There is no evidence of a 'slippery slope' in the Netherlands.

18. The way forward: the Assisted Dying for the Terminally Ill Bill 2004

18.1 The Assisted Dying for the Terminally Ill Bill is much more restrictive than the Dutch legislation. It is closely modelled on the Oregon legislation. The Bill will permit only a competent adult who is suffering unbearably from a terminal illness the right to be able to request medical help to die. That help may be given only by a doctor.

18.2 The patient must be suffering unbearably from the illness and satisfy the attending physician that his request for help to die is made of his own free will.

18.3 Once the attending physician has carried out a thorough examination, has satisfied himself of the patient's medical position, and discussed with the patient all the other options, including palliative care, he must then refer the patient to a consultant physician. The consultant physician must again examine the patient, confirm the diagnosis and prognosis, satisfy himself that the patient is suffering unbearably, investigate all other options, such as palliative care, and satisfy himself that the patient is making the request voluntarily. Palliative care must also be offered independently by a palliative care specialist.

18.4 Only once all these requirements have been satisfied can the patient then make a request for medical help to die, in the form of a declaration which must be witnessed by a solicitor and one other independent person.

18.5 Before the attending physician can help the patient to die, a period of time must elapse so that the patient is absolutely certain that this is what he or she wants to do. The patient must be informed by the doctor of their right to revoke the declaration at any time. Before the attending physician can take the final steps to help the patient to die, he must first check that the waiting period has elapsed, that the declaration has not been revoked, and that the patient still wants to proceed.

18.6 In addition to enabling the patient to ask for help to die, the Bill also puts in place a strict reporting mechanism, so that no longer will medical assistance to die at the end of life go unreported. In short, the Bill provides both choice to the terminally ill person and also a system of safeguards to ensure that this very serious area of medical practice is both transparent and properly regulated.

18.7 The predecessor to this Bill, the Patient (Assisted Dying) Bill, was considered by the Joint Parliamentary Committee on Human Rights in 2003. In their Seventh Report of Session of 2003-03, published on 21 March 2003, the Committee concluded that:

In our view, the safeguards set out in the Patient (Assisted Dying) Bill would be adequate to protect the interests and rights of vulnerable patients. They would ensure that nobody could lawfully be subjected to assisted dying without his or her fully informed consent. We consider that this would respect the right to personal autonomy and self-determination of mentally competent patients under ECHR Article 8.1, and would not be incompatible with the positive obligations of the State to protect life under ECHR Article 2.²⁴

The Assisted Dying for the Terminally Ill Bill is currently being considered by the House of Lords.

24 <http://www.publications.parliament.uk/pa/jt200203/jtselect/jtrights/74/74.pdf>

References

13. Center for Disease Prevention and Epidemiology, (1999), [Oregon's Death with Dignity Act: The first year's experience](#), Oregon Health Division: Oregon.
14. Center for Disease Prevention and Epidemiology, (2000), [Oregon's Death with Dignity Act: The second year's experience](#), Oregon Health Division: Oregon.
15. Center for Disease Prevention and Epidemiology, (2001), [Oregon's Death with Dignity Act: Three years of legalized physician-assisted suicide](#), Oregon Health Division: Oregon.
19. Cleeland C S, Gonin R, Hatfield A K, Edmonson J H, Blum R H, Stewart J A, and Pandya K, (1994), [Pain and its treatment in outpatients with metastasis cancer](#), *New England Journal of Medicine*, 330 (9), 592–6.
11. Davies J, and McVicar A, (2000), [Issues in effective pain control. From assessment to management \(review\)](#), *International Journal of Palliative Nursing*, 6 (4), 162–9.
25. Deliens L, Mortier F, Bilsen J, Cosyns M, Vander Stichele R, Vanoverloop J, and Ingels K, (2000), [End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey](#), *The Lancet*, 356, 1806–1811.
12. Gilron I, Bailey J, Weaver DF, and Houlden RL, (2002), [Patients' attitudes and prior treatments in neuropathic pain: a pilot study](#), *Pain Research and Management*, 7 (4), 199–203.
1. Griffiths J, Bood A, and Weyers H, (1998), [Euthanasia and law in the Netherlands](#), Amsterdam University Press: Amsterdam.
27. Hanks G W, and Forbes K, (1997), [Opioid responsiveness](#), *Acta Anaesthesiol Scand*, 41, 154–158.
3. Kleespies P M, Hughes D H, and Gallacher F P, (2000), [Suicide in the medically and terminally ill: psychological and ethical considerations](#), *Journal of Clinical Psychology*, 56(9), 1153–1171.
24. Kuhse H, Singer P, Baume P, Clark M, and Rickard M, (1997), [End-of-life decisions in Australian medical practice](#), *Medical Journal of Australia*, 166, 191–6.
28. Maddocks I, Somogyi A, Abbott F, Hayball P, and Parker D, (1996), [Attenuation of morphine-induced delirium in palliative care by substitution with infusion of Oxycodone](#), *Journal of Pain and Symptom Management*, 12 (3), 182–189.
22. Magnusson R S, (2002), [Angels of Death: exploring the euthanasia underground](#), Yale University Press: New Haven.
7. Van der Maas P J, van Deldon J J M, Pijnenborg L, and Looman C W N, (1991), [Euthanasia and other medical decisions concerning the end of life](#), *The Lancet*, 338, 669–674.
8. Van der Maas P J, van der Wal G, Haverkate I, de Graaff C L M, Kester J G C, Onwuteaka-Philipsen B, van der Heide A, Bosma J M, Willems D L, (1996), [Euthanasia, physician-assisted suicide, and other medical practices involving the end-of-life in the Netherlands, 1990–1995](#), *New England Journal of Medicine*, 335, 1699–1705.
9. Onwuteaka-Philipsen B D, Van der Heide A, Koper D et al, (2003), [Euthanasia and other end-of-life decisions in the Netherlands in 1990, 1995 and 2001](#), *The Lancet*, 362, 395–399.

20. Mercadante S, Armata M, and Salvaggio L, (1994), [Pain characteristics of advanced lung cancer patients referred to a palliative care service](#), *Pain*, 59, 141–5.
26. Morley J S, Miles J B, Wells J C, and Bowsher D, (1992), [Paradoxical pain \(letter\)](#), *The Lancet*, 340, 1045.
6. McLean S, (1996), [Survey of medical practitioners' attitudes towards physician-assisted suicide](#).
16. Office of Disease Prevention and Epidemiology, (2002), [Fourth annual report on Oregon's Death with Dignity Act](#), Oregon Health Division: Oregon.
17. Office of Disease Prevention and Epidemiology, (2003), [Fifth annual report on Oregon's Death with Dignity Act](#), Oregon Health Division: Oregon.
10. Royal College of Physicians Working Party, (2000), [Principles of pain control in palliative care for adults](#), Online publication found at: http://www.rcplondon.ac.uk/pubs/wp_pc_home.htm
18. Seale C and Addington-Hall J, (1995), [Euthanasia: the role of good care](#), *Social Science and Medicine*, 40(5), 581–587.
29. Sjogren P, and Eriksen J, (1994), [Opioid toxicity](#), *Curr Opin Anaesthesiol*, 7, 465–9.
2. Stenager E N and Stenager E, (2000), [Physical Illness and Suicidal Behaviour](#), in Hawton K and Van Heeringen K (eds), *The International Book of Suicide and Attempted Suicide*, Wiley: Chichester.
4. Sullivan A D, Hedberg K, and Fleming D W, (2000), [Legalized physician-assisted suicide in Oregon – The Second Year](#), *New England Journal of Medicine*, 342: 598–604.
5. Veldink J H, Wokke J H J, Van der Wal G, Vianney de Jong J M B, and Van der Berg L H, (2002), [Euthanasia and physician-assisted suicide among patients with amyotrophic lateral sclerosis in the Netherlands](#), *The New England Journal of Medicine*, 346 (21), 1638–1644.
31. Van der Wal G, van der Maas P, Bosma J M, Onwuteaka-Philipsen B D, Willems D L, Haverkate I, and Kostense P J, (1996), [Evaluation of the notification procedure for physician-assisted death in the Netherlands](#), *The New England Journal of Medicine*, 335:1706–1711.
23. Ward B J and Tate P A, (1994), [Attitudes among NHS doctors to requests for euthanasia](#), *British Medical Journal*, 308, 1332–4.
21. Weinberg H, (2001), [Physician-assisted suicide in Oregon: why so few occurrences?](#), *Medical Journal of Australia*, 174, 353–354.
32. Van der Wal G, van der Heide A, Onwuteaka-Philipsen B D and van der Maas P J, (2003), [Medische Besluitvorming aan het einde van het leven](#), *De Tijdstroom*, Utrecht.
30. Swarte N B, Van Der Lee M, Van der Bom J G, et al, (2003), [Effects of Euthanasia on the bereaved family and friends: a cross sectional study](#), *British Medical Journal*, 327, 189–194.

Appendix I: The number of defendants proceeded against for aiding and abetting a suicide between 1990 and 2001 with outcome of court proceedings

Outcome of proceedings	n^a
Magistrates court	
Total number of proceedings	38
CPS discontinued proceedings	6
Discharged under section Magistrates Courts Act, 1980	6
Charge withdrawn	4
Charge dismissed	2
Committed for trial	1
	25
<hr/>	
Crown Court	
Found guilty ^b	22
<hr style="border-top: 1px dashed #0070C0;"/>	
Sentence	
Conditional discharge	3
Community sentence	10
Full suspended sentence	2
Immediate custody	7

Source: Offending and Criminal Justice Group, Home Office.

a The number of cases.

b Some proceedings still pending.

Appendix 2: The number of reported cases of mercy killing between 1990 and 2002 with outcome of court proceedings^a

Charge	n ^b	Length of sentence	n
Manslaughter	17		
Section 2 of the Homicide Act (1957) ^c	12	18 months	1
		24 months	3
		36 months	4
		48 months	1
		Unknown	3
Section 4 of the Homicide Act (1957) ^d	1	36 months	1
Common Law	4	9 months	1
		12 months	2
		24 months	1
Proceedings not initiated/discontinued on advice from DPP	5		
Suspect committed suicide	11		
Pending	4		
No suspect	1		
Total	38		

Source: Crime and Policing Group, Research Development Statistics Directorate, Home Office.

a Restricted to cases where the person who died was over 18.

b The number of cases.

c Deals with the defence of diminished responsibility.

d Deals with the defence of the pursuit of a suicide pact.

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