Our Right To Die

Lessons for Britain from the European experience

Chris Davies MEP

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The Author

Chris Davies is the Liberal Democrat MEP for the North West of England and a former leader of the Liberal Democrats' European Parliamentary Party.

In 2004 he played a key role in securing the support of his party's conference for the introduction of right-to-die legislation with appropriate safeguards.

He has been a member of the Environment and Public Health Committee in the European Parliament since 1999, and was MP for the Littleborough and Saddleworth constituency 1995-97.

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Note: Throughout this work 'UK' and 'Britain' have been used as shorthand for 'England and Wales'. I recognise that separate legal provision must be made for Scotland and Northern Ireland.

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1. Introduction

When the time comes we all want a good death. For most people the priority will be that it should be peaceful and without pain. Others will want its approach to leave them with the dignity and self-respect of adults able to make decisions for themselves.

Advances in medical care and pain relief have brought huge benefits and relieved many fears yet they cannot address the consequences of every condition or meet the concerns of every individual. Most people will hold on to life to the end whatever the circumstances but for some the prospect of a painful or, in their view, undignified decline is unacceptable.

Some people regard consciousness and the exercise of their free will as vital aspects of a worthwhile existence. Such individuals may rage against the dying of the light by insisting that they should choose for themselves when to turn it off.

Medical assistance to die without distress and with some influence over the timing is an option legally available to patients in some European countries but not in Britain. For a doctor here to respond to a patient's request for assistance to die would place them at risk of prosecution for manslaughter or murder (although no doubt terminal sedation takes place without being recorded), while Section 2 of the 1961 Suicide Act for England and Wales says that a person will be committing an offence if they perform an act:

> *"which is capable of encouraging or assisting another person to commit or attempt to commit suicide, and intends his act to so encourage or assist".*

For many years these words were interpreted as placing at risk of prosecution anyone who helped or accompanied another to secure assistance to die from the Swiss Dignitas organisation. Since guidelines to the interpretation of the law were published by the Director of Public Prosecutions in 2010 these fears have been greatly reduced.[1]

For a price, those who are determined, able, or have help can make a final journey to Switzerland more confident than ever that friends or relatives who assist them face no risk of prosecution, as long as they are not acting from selfish motives. More than 200 people from the UK have now taken this course, and 20-25 more do so every year.[2]

By default, Britain has a policy on medically assisted suicide. It is called 'Switzerland', and it represents an embarrassing failure on the part of British politicians to stand up for the rights of people who are suffering unendurably without hope of recovery.

For why should medically assisted suicide be restricted to those with the ability, the connections or the money? What of those who do not have these resources? What of those who are too defiant and bloody-minded to seek this way out? As Tony Nicklinson responded when asked whether he would make the journey to Switzerland:

> *"Why should I? Why can't I die at home, in my own country, when I choose?"*[3]

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[1] Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide, *Crown Prosecution Service*, February 2010.

[2] As of 28 August 2012, 212 Britons have been assisted to die at Dignitas.

[3] Quoted in "Tony Nicklinson wanted to die, but he also wanted to leave a legacy in law," *The Independent*, 23 August 2012.

Strong Public Support For Reform

The British Social Attitudes survey found in 2010 that 82% of respondents believed that a doctor should probably or definitely be allowed to end the life of a patient with a painful incurable disease at their request. Yet a change in the law to allow people here to seek medical help to die has so far been blocked by a minority with views that are out of step with public opinion.

For some, opposition to right-to-die legislation stems from religious or ethical conviction - strengthened no doubt by a strong element of self-righteousness. In her pamphlet, Assisted Suicide, the polemicist Christina Odone makes clear through her references to "*Doctor Death*", "*second class human beings*" and "*The death squad*" what will be the consequence of reform:

> *"The elderly, people with severe disabilities, the mentally instable, and those with terminal illnesses will be presented with self-inflicted death as a natural, normal and expected final solution."*[4]

The motives of such opponents of reform may be compassionate. They can always be heard expressing the greatest sympathy when intelligent individuals like Tony Nicklinson insist that the circumstances of their life are intolerable. Yet their actions are not compassionate; they are callous and cruel.

To force people suffering unendurably to stay alive against their will can be regarded as a form of torture.

The only valid argument for denying the wishes of such people is that it is necessary for the good of society. Some critics of change nurse genuine fears that it would have unintended consequences, and that the vulnerable might become prey to abuse. The experience of our European neighbours proves these fears to be groundless.

Legislation that enables medical assistance to die is on the statute books in Belgium, the Netherlands and Luxembourg, and in the Dutch case has in practice been established for some 40 years. It demonstrates that a

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[4] Christina Odone *Assisted Suicide: How the chattering classes have got it wrong,* October 2010, p58 (author's emphasis).

change in British law could be wholly beneficial, giving comfort to individuals forced to live with intolerable suffering, and without giving rise to adverse consequences.

The evidence from the Benelux countries is that legislation incorporating measures to prevent the risk of abuse is entirely practical, and quickly ceases to be controversial.

It is time for politicians in Britain to curb their hand-wringing. The death of campaigners like Diane Pretty, who unsuccessfully challenged the assisted suicide law before her death in 2002, and Tony Nicklinson should no longer be greeted with mere expressions of sympathy. It should be marked by practical demonstration that their wishes shall be respected and the law will be changed.

2. The BENELUX Laws

The current debate in the UK follows a pattern that is not new. Public attitudes in Belgium, the Netherlands and Luxembourg were also shaped by a succession of high profile cases in which mentally competent adults with distressing conditions made explicit their wish to die. Political exchanges were heated with strong views expressed on both sides. Legislation introducing statutory requirements was eventually introduced and reform proposals were in 2002 carried by 46-28 in the Dutch Senate and by 44-23 in the Belgian Senate.

However, there is one very clear difference between the debate here and the Benelux experience. Supporters of right-to-die legislation in the UK almost invariably argue for medical assistance to be limited to prescribing the means of bringing about a peaceful death, with the patient retaining direct and sole responsibility for administering the necessary barbiturate by mouth or intravenous drip, imitating the practice in Switzerland and the US state of Oregon. Voluntary euthanasia would remain illegal. By contrast, in the Benelux countries it is common for the doctor to intervene directly, helping their patient to die by way of fatal injection in response to an explicit request.

The Dutch precedent

Arrangements in the Netherlands developed through case law over more than two decades, stemming from a 1973 test case brought after a doctor had responded to a patient's requests to end her own life. The one week suspended sentence she received prompted a public outcry.

Public support for the principle of voluntary euthanasia or assisted suicide grew from 50% in the 1960s to 90% by 1998.[5] Attempts to clarify and codify medical practice were blocked for some years by Christian Democrats in Parliament before being secured through the Termination of Life on Request and Assisted Suicide (Review Procedures) Act which came into force in 2002.

Dutch law makes clear that a doctor who terminates a patient's life on request, or assists a suicide, will not face prosecution if the death is reported to the coroner and it can be demonstrated that statutory 'due care' safeguards have been met. These require evidence that the patient's suffering was 'unbearable' (a subjective judgement and one that can finally be determined only by the individual concerned after due medical consultation) and that there was no prospect for improvement in the condition.

A 'voluntary and well-considered request' must have been made, and the clinical judgement of the patient's doctor must have been supported by a second physician who was satisfied that the criteria had been met.

A doctor providing the means of death must be satisfied that their patient is mentally competent to assess the reality of their medical condition and make the request to end their life. If doubt exists then a specialist should be consulted, and it has become expected practice that the advice of a psychiatrist be sought if the doctor suspects that the patient is suffering from depression.

The patient has to be 18 or over, although there is legal provision also for requests by minors to be accepted in exceptional cases - 16 and 17 year olds must have their parents involved in the discussions with the doctor, and 12-16 years olds must have specific parental consent. The extent of the patient's misery and suffering, and the soul-searching, emotional turmoil and grief of the parents that must accompany decisions of this kind can scarcely be imagined.

Information regarding each assisted death must be submitted to a regional review committee, comprised of a doctor, a legal advisor and an expert in the field of ethics or philosophy. The committee considers

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[5] 'Changes in Dutch opinions on active euthanasia, 1966 through 1991', Van der Maas, P et al (1995) & 'The Dutch Seek to Legalize Long-Tolerated Euthanasia,' *New York Times*, 20 June 2000.

whether the conduct of the case was in compliance with the statutory criteria and, if doubts exist, can forward a case to public prosecutors for further investigation.

The wording of the law allows some flexibility to reflect the realities of each situation. A patient suffering from a progressive and paralysing illness such as motor-neurone disease may have months in which to discuss their state of health and future intentions. They may make clear repeatedly to their doctor that the time will come when they may regard their state of being, or the prospect of a distressing death, as unacceptable and that they will seek support to die at a time of their choosing.

On the other hand, some cancer patients may not decide until very late in the day that they want such help, perhaps only when faced with the prospect of requiring pain relief medication so strong that it will deprive them forever of the opportunity to say goodbye to loved ones.

Provision is made in the legislation for an advance declaration authorising euthanasia in case the patient later becomes incompetent. There is no absolute requirement that the patient's condition necessarily be terminal.

Experience in Belgium and Luxembourg

Legal changes in Belgium followed some years of informal toleration of voluntary euthanasia. It was said that as many as one in 10 deaths were the result of doctors applying medication knowing it would hasten their patients' ends, although in almost all cases such a death was only hours or days away.[6] Prosecutions were rare, as they are today in the UK despite claims that similar practices are not uncommon here.[7]

Political will was necessary to bring about change and the formation of a Socialist-Liberal-Green coalition government provided the conditions. Led by Liberal Prime Minister Guy Verhofstadt, now the leader of the Liberal Democrat (ALDE) group in the European Parliament, it was the

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[6] "Belgians follow Dutch by legalising euthanasia," *The Guardian*, 26 October 2001.

[7] In "National survey of end-of-life decisions made by UK medical practitioners", Seale C, (2006), and "End-of-life decisions in the UK involving medical practitioners", Seale C, (2009) Clive Seale surveyed doctors in the UK about end of life care. He found that euthanasia occurred in 0.5% of all deaths reported in both surveys.

first for many years to include no members from parties committed to particular religious beliefs.

With opinion polls indicating 85-93% support legislation was approved in May 2002.[8] It made voluntary euthanasia legal for those in a

> *"medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by illness or accident".*

The Belgian Act of Euthanasia stipulates that a request for assistance to die can only come from a patient who is legally competent. It must be 'completely voluntary' and 'not the result of any external pressure'. The doctor concerned must have 'several conversations with the patient spread out over a reasonable period of time' to assure themselves of the extent of suffering and to confirm that the request for assistance to die is consistent and enduring.

The patient's doctor must report the euthanasia to the Federal Control and Evaluation Commission. Comprised of eight doctors, four practising lawyers or professors of law, and four people representing the interests of patients, the Commission is responsible for regulating the practice and assessing whether any prosecution is appropriate.

Luxembourg's Law of 16 March 2009 on Euthanasia and Assisted Suicide is closely based on the Belgian equivalent but specifically permits medically assisted suicide as well as voluntary euthanasia. The law was passed despite the opposition of the country's monarch, Grand Duke Henri, whose use of the veto over the matter led to the country's parliament amending the constitution to enable it to come into force.

The recent passage of the legislation, and the small size of the country's population, means that Luxembourg provides few sources from which to draw statistical comparisons.[9]

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[8] Raphael Cohen-Almagor, "Euthanasia Policy and Practice in Belgium: Critical Observations and Suggestions for Improvement", *Issues in Law & Medicine*, Vol. 24, No. 3, 2009.

[9] The 2009/10 annual report of the Luxembourg Review Committee on Euthanasia and Assisted Suicide cover the five cases that were reported in that year - the first since enactment of Luxembourg's euthanasia law.

In Belgium and Luxembourg additional checks are required if the patient does not have a terminal illness, requiring consultation with a specialist in the field, or a psychiatrist, and an additional delay of at least one month. Belgian law also requires that the patient's request be made in writing (in contrast to the Netherlands where written requests are not encouraged to ensure that patients need feel under no obligation later to act upon them). Most hospitals in Flanders also insist that patients be informed about the palliative care options available to them.

3. Who Seeks Help To Die?

A study of 1,917 reported cases of voluntary euthanasia in Belgium over the period 2003-7 identified that 82.5% of patients had suffered from cancer.[10] In the Netherlands too, cancer patients comprise the largest group seeking assistance to die.[11]

The 2006 annual report of the Belgian federal review committee suggested that doctors estimated the life expectancy of their patients to be no more than "a few months". Professor Heleen Dupuis in the Netherlands suggests that in most cases voluntary euthanasia or medically assisted dying make a difference of only a week or so.[12]

Dr Luc Deliens, a Belgian professor of public health and palliative care, claims that in 80-90% of cases patients receiving voluntary euthanasia are within hours rather than weeks of death. [13]

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[10] Tinne Smets et al, "Legal Euthanasia in Belgium - Characteristics of All Reported Euthanasia Cases", *Medical Care*, Vol. 2 No. 12 December 2009.

[11] Paul van der Maas et al "Two Decades of Research on Euthanasia from the Netherlands. What Have We Learnt and What Questions Remain?" *Journal of Bioethical Inquiry*, September 2009.

[12] Author's interview with Professor Heleen Dupuis, a Dutch Senator and Professor of Medical Ethics, July 2010.

[13] Author's interview with Professor Luc Deliens, a Professor of public health and palliative care and head of the end-of-life care research group at Vrije University in Brussels, September 2010.

The circumstances of every patient will be different but clearly a majority are close to the end. Many people who have watched someone go through this time, perhaps being given larger and larger doses of morphine, will know that it is a period during which life provides few rewards and at the least some discomfort, alleviated perhaps by a drug-induced lack of consciousness. This may be the common experience of many but it is not the way that all want to go. Some people determine beforehand that they want to chart a different course.

> *"Patients want to live as long as they can, but they don't want to suffer. You have to give people the freedom of choice."* - Jean-Jacques de Gucht, Belgian senator [14]

What may come as a surprise is the age of the patients concerned. Fewer than 18% of cases in the Belgian study involved people aged 79 or more, although more than half of all deaths are from this age group. Conversely, the 40-59 age bracket generated more than a quarter of the cases of voluntary euthanasia although comprising less than a tenth of all deaths.[15]

The research suggested that a typical patient seeking help to die was aged 40-79. It may be that the age profile is relatively low because these are people in full command of their senses and quite able to make a well informed decision about their future. Perhaps in some cases they nurse a degree of anger that fate has dealt them a poor hand by robbing them of years of life.

This would support the observation that individuals who request help to die tend to be strong willed, very aware of what they want for themselves, and very determined that they and not their disease should have the final say over the timing of their death. Far from being amongst the most vulnerable in society they are likely to be amongst the better educated and most self-confident.

Such a description certainly applies to many of the British citizens who have travelled to Switzerland to secure assistance from Dignitas. The reality is very different to the myth propagated by the opponents of reform that the weak and helpless are coerced into a premature death.

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[14] Author's interview with Jean-Jacques De Gucht, VLD Senator, September 2010.

[15] Smets et al, 2009 *op. cit.*

> *"I tell patients with advanced cancer that I will offer euthanasia. It keeps them alive. They almost always choose to live longer."*
> - Prof. Jean-Louis Vincent, Erasme Hospital, University of Brussels[16]

In Belgium and the Netherlands it is claimed that two thirds of the requests to die put to doctors are either refused or not acted upon.[17,18] Sometimes treatment provides sufficient relief, while in other cases death intervenes before a final decision is made. Either way, the option of an assisted death serves as a comfort rather than as a threat.

The unbearable becomes more bearable and for longer because there is a means of escape.

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[16] Author's interview with Professor Jean-Louis Vincent, Head of the Intensive Care Unit at Erasme University Hospital and Professor of Intensive Care Medicine at the University of Brussels, August 2010.

[17] Onwuteaka-Philipsen et al, "Evaluation of the Euthanasia and Assisted Suicide Act", 2007.

[18] Penney Lewis & Isra Black "The effectiveness of legal safeguards in jurisdictions that allow assisted dying", January 2012.

4. The BENELUX Safeguards

Opponents of reform in the UK claim that right-to-die legislation would inevitably come to be used in ways not intended. No safeguards could be incorporated that would prevent abuse. Christina Odone writes in her pamphlet:

> *"Once assisted suicide becomes legal, it will slide into voluntary euthanasia which in turn will lead to involuntary euthanasia....In short, legalising euthanasia will change our lives forever. Our world will become a harder, more selfish place, where the weak will have no value."*[19]

Yet this assertion is flatly contradicted by experience in Belgium, the Netherlands and Luxembourg. The procedural safeguards incorporated within the laws of these countries have proven completely effective. The patient retains control, and the wishes of the individual are paid respect that is denied and rejected in Britain.

> *"Since the law was introduced in 2002 there has not been one prosecution. Sometimes the review committee has rapped knuckles because a doctor has failed to comply in every detail with the requirements, but no doctor has failed properly to consider the circumstances."* - Dr Rob Jonquiere, NVVE-NL[20]

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[19] Odone, C *op. cit.* p.6

[20] Author's interview with Dr Rob Jonquière, Managing Director of NVVE, July 2010.

The requirements of the legislation are slightly different in each of the Benelux countries but collectively they include a range of safeguards that could be incorporated when fashioning a British right-to-die law.

Central to any case of medically assisted death is the role of the patient's doctor and this provides the first and most important safeguard. A doctor who provides assistance to die remains liable to prosecution unless it can be demonstrated that in assessing the patient's request all the legal requirements have been met.

The patient must be:

- An adult
- Mentally competent
- A citizen or resident (not a visitor)
- Suffering unendurably with no hope of recovery

The procedure requires that:

- An explicit and entirely voluntary request is made verbally, and perhaps in writing, to the patient's doctor repeatedly over a period of time
- The request is 'well considered'
- There is no evidence of any family pressure upon the patient
- A second doctor examines the patient and confirms the serious and incurable nature of the condition
- The opinion of a psychiatrist is provided if there is any doubt about the patient's mental competence
- All cases are fully documented and a report is subsequently presented by the patient's doctor to an independent monitoring body that reviews the evidence and, if necessary, may recommend a criminal investigation by the prosecuting authority
- No doctor can be required to provide a patient with assistance to die if this is contrary to their conscience, but, if so requested by the patient, they must transfer the medical record to another doctor designated by the patient

"There will never be perfection. But by human standards this is pretty good. By legal standards this control system is about as good as there is." - Prof. John Griffiths, Legal Theory Dept, Groningen University speaking about the system in the Netherlands[21]

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[21] Author's interview with Professor John Griffiths, Professor of Sociology of Law at the University of Groningen, August 2010.

5. The Safeguards In Practice

Of 7,487 cases in the Netherlands where assistance to die was provided over the period 2007-9 just two led to criticism that the unbearable suffering criterion had not been met in full.[22] In Belgium, of 1,917 cases over the five years 2002-7, unbearable suffering was demonstrated in all but 22. In seven of these cases the patient was comatose and approaching death, with euthanasia being administered on the basis of the patients' advanced requests. In the remaining cases extreme suffering had yet to commence but was a medical certainty and there was no prospect for improvement.[23]

It is expected in the Netherlands that a doctor should know their patient sufficiently well to assess whether the due care criteria have been met. Belgian law requires the physician to have had 'several conversations with the patient spread out over a reasonable period of time' so that they are convinced of the patient's suffering and their determination to bring it to an end.[24]

Whether these formal obligations can always be met as intended when a

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[22] Reports of the Regional Euthanasia Review Committees 2007 & 2009, cited by Lewis & Black *op. Cit.*

[23] *Ibid.*

[24] An English language translation of the Belgian law can be read online at http://tinyurl.com/belgianlaw

patient makes a request to die while already close to death, or where a new physician has been introduced because the patient's own doctor has registered a conscientious objection, may prove a moot point.

In all the Benelux countries a second, independent, doctor must also see the patient and give an opinion as to whether the 'due care' criteria have been met. In the Netherlands many of the doctors consulted for a second opinion will be acknowledged as having experience in making such judgements rather than simply being selected at random.

Of the instances cited above the consultation criterion was judged not to have been properly met in 11 out of the 7,487 Dutch cases: eight because the consulting physician was considered not to have been sufficiently independent; two because no such consultation had been undertaken, and one because the patient had to wait five months after consultation for euthanasia to take place. Of the 1,917 Belgian cases it was accepted that a second, independent physician had been consulted in 99.8% of all instances.

Both Belgian and Dutch laws require that the physician reports cases of euthanasia to monitoring and review bodies, which can refer them to public prosecutors if the requirements of the law have not been met. More than 80% of cases in the Netherlands are now thought to be formally reported.[25]

The failure to secure full compliance is attributed to differences in interpretation of individual circumstances. Doctors who make a clinical judgement to alleviate suffering by increasing levels of sedation, with the patient kept asleep but not fed or hydrated until death occurs, may not regard the situation as constituting euthanasia within the meaning of the legislation. In medical terms their actions are unlikely to be different from those of doctors elsewhere.

It has to be emphasised that circumstances vary from one case to another. It is straightforward to define a pre-meditated case of voluntary euthanasia where consultations have taken place over a period of time and every box has been ticked. The judgement is not so easy when a patient has expressed their will very clearly but is then overtaken by the illness and loses full consciousness.

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[25] Smets et al, 2009 *op. cit.*

> *"The Dutch have not had any Dr Shipman cases or indeed any major scandal. I think in the Netherlands it would be harder to happen."* - Prof John Griffiths, Legal Theory Department, Groningen University

The legislation in all the Benelux countries places great responsibility and trust in the doctors involved, and perhaps the degree of trust is greater than will be found in Britain. Yet life and death decisions are made by medical practitioners everywhere and there must always be a degree of trust. In the Netherlands every death is formally scrutinised by a city medical official; some problematic cases may escape undetected but not mass murder as in the British case of Harold Shipman.

Doctors in the Netherlands are aware that when they help a patient to die within the terms of the legislation the details of the case will be subject to review. Their reputation, and perhaps their liberty, may be placed at risk. Those who claim that reform in Britain would place vulnerable people at risk must explain why any doctor should accede to such a request.

Since the passage of the Dutch legislation review committees have occasionally criticised doctors for failing to tick all the boxes and comply with 100% of the required criteria, but in no case has it been suggested that they so failed to assess the particular circumstances as to warrant criminal prosecution. In Belgium too no prosecution of a doctor has yet been warranted.

6. The Floodgates Stay Closed

Critics of the Benelux laws claim that they have led to an increase in the number of patients whose death is brought about through voluntary euthanasia. This assertion requires a selective interpretation of the data but feeds the hysteria of British opponents of reform.

> *"Don't imagine that, if assisting suicides were to be legalised, we would see the same number and type of cases as we do now. Take away the deterrent effect of the law, and we could expect to see more cases, many of them with evidence of serious abuse. It's a dangerous road down which we should not go."* - Lord Carlile.[26]

It might be expected that following the passage of legislation there would over time be an increase in the number of assisted suicide deaths, although they would still remain a tiny proportion of the whole. This might be thought a natural consequence of the subject being debated more openly, of current but discreet medical practice being properly recorded, and of patients recognising that an option was open to them that had previously been closed.

What is surprising is that it is unclear whether any such increase has in

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[26] Lord Carlile in All Party Parliamentary Group "Dying Well," *Parliamentary Brief* March 2009.

fact taken place in Belgium or the Netherlands. Annual fluctuations in the figures make their interpretation difficult and trends hard to detect. Statistical increases in the number of registered voluntary euthanasia deaths may have been at least matched by a decline in the number of such deaths that were previously not classified in this way.

> *"In most countries assisted suicide is illegal, invisible and uncontrollable. When it is made legal it becomes one of a number of options that patients can consider."* - Sophie In't Veld, Dutch MEP[27]

In 1995 there were 3,527 cases of voluntary euthanasia recorded in the Netherlands, and 3,800 in 2001, representing some 2.3% of all deaths. A significant fall in the number was registered in 2002 but thereafter numbers increased gradually to 3,136 in 2010.[28]

A recent Lancet study gave no support to the suggestions that voluntary euthanasia in the Netherlands is growing inexorably. Its own analysis found that the "rate is higher than the 1.7% in 2005, but comparable with those in 2001 and 1995", and it suggested that doctors had acquired greater confidence in the legal framework.[29]

Other research confirms this, indicating that the reporting of cases has improved over the years.[30]

In Belgium the reported figure has risen incrementally since the legislation was agreed, although the proportion of voluntary euthanasia deaths each year remains less than 1% of the total. 347 cases were reported in 2004, and 495 cases reported three years later.[31] However, taking into account the inadequacy of previous reporting of voluntary euthanasia and terminal sedation some claim that the total number of cases has actually declined.

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[27] Comment made in correspondence with the author, September 2012.

[28] Numbers supplied by NVVE and the annual reports of the Dutch regional review committees.

[29] Onwuteaka-Philipsen et al, "Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey", *The Lancet*, Early Online Publication, 11 July 2012.

[30] From 54% in 2001 to 80% in 2005 according to Mette Rurup et al "The reporting rate of euthanasia and physician assisted suicide. A study of the trends." *Medical Care 46 (12)*, 2008.

[31] Smets et al, op. cit.

7. No Slippery Slope

However much public support there may be for assisted suicide legislation, campaign groups opposed to reform propagate the fear that 'any change in the law to allow assisted suicide or euthanasia would place pressure on vulnerable people to end their lives for fear of being a financial, emotional or care burden upon others. This would especially affect people who are disabled, elderly, sick or depressed'.[32]

Sometimes the language of the opponents strays into the realm of the ludicrous, hinting that they believe supporters of right-to-die legislation would sanctify eugenics.

> *"If we legalise suicide, we risk having a strident elite condemning the less fortunate to a premature death. For it is the marginalised, the disabled, the less articulate and the poor who are most likely to be under pressure to accelerate their death...Those working with the elderly, the disabled, and the terminally ill worry that, once introduced on compassionate grounds, assisted suicide will lead to death on request or euthanasia without consent...The danger is that less-than-perfect citizens will be deemed expendable."* - Christina Odone[33]

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[32] Care Not Killing 'What we do' at www.carenotkilling.org.uk/about/what-we-do/

[33] Odone 2010, op cit, pp 4-5.

The implication of such claims is that there are people lining up to bring about the death of relatives who are constrained only by the law as it stands. Yet Keir Starmer, the Director of Public Prosecutions, has said that in the 18 months following publication of guidelines to interpret the Suicide Act he personally oversaw all the cases where a suicide had been assisted and had

> *"not encountered one where an individual was motivated by the prospect of gaining in some way from the death of the victim".*[34]

> *"Euthanasia existed before the current legislation but then it was outside the law. When we legalised it we reduced abuse."* - Belgian senator Jean-Jacques de Gucht

The 'slippery slope' argument was tested in Dutch academic research which questioned whether there was evidence of any disproportionate impact on 10 groups of potentially vulnerable patients. The results showed no heightened risk for the elderly, women, the uninsured, people with low educational status, the poor, the physically disabled or chronically ill, minors, people with psychiatric illnesses including depression, or racial or ethnic minorities, compared with background populations. Nor was there any evidence that any of these groups felt some kind of 'duty' to die rather than be a burden to others.[35]

> *"Disabled people being encouraged to die? The contrary is true. Doctors are afraid of being seen to act immorally. They want to avoid any suggestion of bad practice."* - Heleen Dupois, Dutch senator, professor of medical ethics and former NVVE (Right to Die-NL) president

In Belgium the Vrije University of Brussels End-of-Life Care Research Group confirmed that there were no significant changes in demographic characteristics of cases between 2002 and 2007.[36]

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[34] Keir Starmer, Director of Public Prosecutions "So far we have got it right on assisted suicide - largely thanks to you, the public", *The Times* 6 September 2011.

[35] Ganzini et al "Legal Physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups", *Journal of Medical Ethics*, July 2007.

[36] Details given in presentation by Professor Luc Deliens: www.senat.fr/rap/r09-579/r09-579-annexe.pdf

Concern here that right-to-die legislation may put the disabled at risk rests on the assumption that doctors and a review panel may judge requests to die as logical and understandable. But in the Benelux countries disability in itself does not provide justification for a doctor to help their patient to die. In Belgium, if a request comes from someone who is not terminally ill then a third physician, a psychiatrist, or specialist in the illness from which the patient suffers must be consulted, and a month must elapse between the written request and the voluntary euthanasia. The patient has to demonstrate unbearable and implacable physical or mental pain.

> *"The safeguards work. We are past the point in public debate when people challenge the sense of the law."* - Jean-Jacques de Gucht, Belgian senator

Christina Odone could hardly have been more dramatic in spelling out her fear about the wave of malevolence she believes would sweep over us as a consequence of right-to-die legislation. The slippery slope could hardly be better polished.

> *"Pressure will grow for euthanasia to be applied more widely; if it is the best interest of competent patients, why should it not be foisted upon the elderly, who might be persuaded that they were a burden? Or on minors, who also cannot speak for their best interest? Or on the mentally incompetent who cannot know what is their best interest?"* - Christina Odone[37]

Yet the experience of the Benelux countries (as well as from Switzerland and Oregon) demonstrates these claims to have no foundation at all. The legal framework has created an option that provides relief for a small number of individuals, but it is neither part of the mainstream of public health policy nor has it led to changes in social attitudes.

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[37] Odone, 2010 op. cit. p14

8. Assisted Dying Complements Palliative Care

Effective palliative care provision for terminally ill patients and the introduction of assisted suicide legislation are not either-or options. There is no competition between them.

Human beings rarely choose to give up life prematurely, and the vast majority of those nearing the end of their days will always seek to let nature take its course. Those who argue the case for right-to-die legislation entirely agree that the provision of palliative care services should be a priority for government health policy. Medically assisted suicide can never be regarded as a 'policy'; it is simply an option that some people should have the right to choose.

Respect for individual wishes is central to the patient-centred ethos of palliative care. Ensuring that the right to gain assistance to die is available should be considered as part of the whole; it is entirely in accordance with the importance attached in palliative care to the psychological needs of each patient. The difference between pain relief to the point of unconsciousness until death and medically assisted suicide is in any case largely a matter of premeditated choice.

BENELUX palliative care

Opponents of reform suggest that our European neighbours have elevated voluntary euthanasia into the mainstream of public policy. The Daily Telegraph has referred to

> *"the collapse of the palliative care system in the Netherlands following the legalisation of euthanasia".*[38]

Christina Odone suggests that the Benelux countries support assisted dying

> *"because there is, simply, no adequate alternative."*[39]

Others have been even more explicit. Alex (Lord) Carlile has gone so far as to state that

> *"The Netherlands - let us be realistic about this - is a country where euthanasia is used as an alternative to an expensive palliative care system that it does not have."*[40]

Palliative care provision in the UK is recognised as being amongst the very best in the world. That said, it has its failings: the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) reported in 2011 that 71 hospitals in the UK appeared to have no acute pain services, and that some elderly patients died only after experiencing great distress.[41]

But the quality of provision here is no reason to damn that of others. The health services of the Benelux countries also enjoy a fine reputation. In its 2011 'Quality of Life Index', The Economist compared end-of-life care services in 40 countries, assessing their cost, quality and availability. While the UK and Australia topped the table Belgium came 5th and the Netherlands 7th, favourable positions compared to France (12th), Italy (24th) and Spain (26th) where no right-to-die laws exist.[42]

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[38] "Euthanasia cases in Holland rise by 13 per cent in a year", *Daily Telegraph*, 20 June 2010.

[39] Odone, 2010 op. cit. P36

[40] Hansard HC debate 12 July 2006, Col. 1192.

[41] NCEPOD report "An Age Old Problem: A review of the care received by elderly patients undergoing surgery", 2011.

[42] Economist Intelligence Unit "The quality of death: ranking end-of-life care around the world", 1 July 2010.

To suggest that the Benelux countries have used right-to-die legislation as a means of avoiding expenditure on palliative care is not only false but downright insulting. Precisely the opposite is true. The right-to-die laws have stimulated investment in palliative care provision, not only by promoting public discussion and raising awareness of the need but because they have embarrassed politicians into demonstrating that voluntary euthanasia is not an alternative to healthcare provision. Details of investment and provision of facilities published by the European Association for Palliative Care support the argument.[43]

Els Borst, the D66 (Liberal) party health minister who in 2002 steered assisted dying legislation onto the Dutch statute book had promoted, four years previously in 1998, a specific programme to stimulate palliative care in her country. The two initiatives were not contradictory she has explained. In her view voluntary euthanasia can be regarded as a final element in a 'successful palliative care trajectory'.[44]

Belgian parliamentarians approved a palliative care law at the same time as they legalised voluntary euthanasia, resulting in a 72% increase in federal funding over the following five years to support the requirement that every hospital should have a palliative support team.[45] It has been claimed that "every village in Belgium can provide patients with palliative care in their own home"[46], while the NVVE (Right to Die-NL) suggests that palliative care provision is now made in every Dutch hospital.

Professor Luc Deliens says that palliative care should, 'of course', always be the first option for the terminally ill,

> *"but within palliative care you have to take end-of-life requests from patients very seriously because it is about the patient not*

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[43] European Association for Palliative Care "Palliative Care Development in countries with a Euthanasia Law", October 2011.

[44] In response to a book referenced by the article "Now the Dutch turn against mercy killing", *Daily Mail,* 9 December 2009, Els Borst wrote a rebuttal entitled "I am not of the opinion that the Euthanasia law was implemented too fast". A copy of her letter and an English translation is at tinyurl.com/borstletterdoc

[45] European Association for Palliative Care, October 2011.

[46] Author's interview with Luc Deliens, *op. cit.*

the disease. Pain doesn't always come top of the list, existential suffering is key and that can include the inability to do the things that make life seem worthwhile. Euthanasia is part of palliative care. The patient must be able to trust the doctor to put their wishes above all else".

9. Competent People Making Decisions For Themselves

At the heart of the argument in support of a right-to-die law is the principle that competent, rational adults in distressing circumstances should have the right to make their own decision about how their life will end.

Baroness Findlay has claimed that 'overseas experience' suggests that some people have been helped to die even though they were not competent to make such a commitment.[47] There is no firm evidence from the Benelux countries to support such a claim. An assessment of the competence of the patient is one of the safeguards required in those countries where medically assisted death is allowed.

My colleague, Vince Cable, has posed the question: "Many of us have seen parents descend into mental confusion. Does a request from a confused relative for help to end it all constitute a request for assisted suicide?"[48] The simple answer is 'NO'.

A doctor who assisted the death of a patient who was confused and therefore unlikely to be mentally competent would be committing a crime

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[47] Baroness Findlay speaking in *The Observer* round table discussion "A matter of life, death and assisted dying", 31 January 2010.

[48] "Assisted Suicide should never be just another choice," *Daily Mail* 14 December 2009.

and could face prosecution.

In the Netherlands the attending physician has to consult a psychiatrist if they suspect the patient is not competent. In Belgium there is a mandatory additional consultation with a psychiatrist or relevant specialist if the request comes from a patient who is not terminally ill.

Opponents of reform frequently suggest that patients may seek help to die because they are depressed, implying that this would render them not competent to make such a decision.

In the Benelux countries symptoms of depression do not of themselves preclude a doctor from providing assistance to die; after all, it is hardly unlikely that someone suffering unendurably with no hope of recovery will show some symptoms of depression. On the other hand such symptoms may result from the effects of the illness or of the treatment being prescribed.

A 1995 Dutch study identified depression as the predominant symptom in just 3% of all assisted death cases, compared with 'loss of dignity' in 60%.[49] Another study showed that the presence of depressive symptoms were six times more prevalent in people who had been refused their requests for euthanasia than in those in which it was granted.[50]

The patient's doctor, whose primary duty is to their well-being, must make an initial assessment as to whether a request to die stems from depression. Even more important, they must determine whether they are competent to make a decision about their future.

Laws everywhere presume that individuals are competent to make decisions and take responsibility for their actions unless it can be proven otherwise. Ultimately the judgement about whether someone's disability is so inhibiting as to cause a patient implacable mental pain is one only the patient can make. In the words of Tony Nicklinson:

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[49] Van der Maas et al "Euthanasia, Physician-Assisted Suicide, and other medical practices involving the end of life in the Netherlands, 1990-1995", *New England Journal of Medicine*, November 1996.

[50] BD Onwuteaka-Philipsen et al, "The last phase of life: who requests and who receives euthanasia or physician-assisted suicide?" *Medical Care 48*, 2010.

"In Britain, everyone is legally allowed to commit suicide, but I am denied the right only because I am so severely disabled. How do you defend this discrimination against me?"[51]

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[51] "Tony Nicklinson's Agonizing Plight Shouldn't Change the Law", *Huffington Post,* 22 June 2010.

10. No Second Chance

What if the decision to give a patient assistance to die has been based on the wrong premise? What if a cure could be discovered for their ailment? Opponents of reform often cite examples of people with seemingly terminal illness who once expressed a wish to die only to outlive the prognosis and live on without pain.

'Miracles' may sometimes happen, but the assumption that they will happen cannot be used as a basis for public policy.

The Royal College of Pathologists told a House of Lords select committee that as many as one in 20 diagnoses of terminal illness were inaccurate.[52] Dignity in Dying has highlighted three studies which found that between 63% and 71% of prognosis predictions were too optimistic.[53]

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[52] Select Committee on the Assisted Dying for the Terminally Ill Bill Report (HL Paper 86-I) 1995.

[53] Stiel et al "Evaluation and comparison of two prognostic scores and the physicians' estimate of survival in terminally ill patients", *Supportive Cancer Care 18: 43-49,* 2010; Christakis NA, Lamont EB "Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study" *British Medical Journal 320:469-472,* 2000; Gripp S, Moeller S, Bolke E et al "Survival prediction in terminally ill cancer patients by clinical estimates, laboratory tests, and self-rated anxiety and depression" *Journal Clinical Oncology* 25:3313-3320, 2007.

Doctors can only make the best assessment they can, and must share the prognosis honestly with their patients.

> *"Doctors do not want to kill patients. Their whole ethos is to keep patients alive. Death is a failure. So patients have to convince their doctor of their determined will to die."* - Prof Luc Deliens

Supporters of right-to-die legislation seek to ensure that the wishes of patients are respected. Opponents of reform insist that these wishes should be denied - so long as the individuals concerned are dependent upon others and unable to help themselves. Those who base their opposition on some personal religious or ethical code should examine their consciences.

11. Public Support For BENELUX Laws

The passage of assisted suicide legislation can be controversial. The arguments for and against cross the usual political divides and can set colleague against colleague. In Luxembourg the debate provoked a constitutional crisis. Yet experience suggests that once the law is in place the heat dissipates. The focus shifts from public argument to the private consultations that take place around a patient's bed.

In the Netherlands the NVVE claims that the right-to-die principle had 85% public support in 1998 and that the proportion now exceeds even that. It has itself a membership base of 135,000.[54] A survey conducted in 2012 by three major teaching hospitals found an astonishing 93% of respondents in favour of the voluntary euthanasia legislation.[55] During the 2010 general election the issue was not raised in any party manifesto and no candidate was asked to take a position.

Belgian senator Jean-Jacques de Gucht claims that the law commands 80-90% public support in his country and has the backing even of many conservative politicians. Professor Luc Deliens backs up this assertion, suggesting that virtually no-one in Belgium now speaks against the right-to-die legislation and that there are even some Jesuit doctors who support it. No political party in the country is campaigning to overturn it.

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[54] Author's interview with Rob Jonquière, Managing Director of NVVE, 27 July 2010

[55] www.elsevier.nl/web/Nieuws/Wetenschap/300942/Meeste-artsen-tegen-euthanasie-bij-dementie.htm

12. The Swiss Alternative

Help to secure medically assisted suicide is available in the UK to some British citizens but not to others. Those who are able, and who have the financial resources and the assistance, can make their way to Switzerland to seek the help of Dignitas ('to live with dignity - to die with dignity'), an organisation that since 1998 has provided counselling and suicide-prevention advice but also, if the patient is determined, assistance to end their lives.[56]

Dignitas has provided a means of escape both for the individuals who have sought its help and for British politicians anxious to avoid making a decision.

> *"I know that I am more fortunate than many other people in my situation, in that I have the knowledge and the finances and the support of my family to make assisted suicide in Switzerland possible. To die with dignity should be everybody's right."* - Dr Anne Turner[57]

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[56] Dignitas confirmed in correspondence with the author that they take financial circumstances into account and exempt many members from the cost of membership. Some members have paid nothing. But financial resources are still required to make the journey.

[57] "By the time you read this, I will be dead", *The Daily Telegraph* 25 January 2006.

But if the money is not available, if the pain, discomfort or paralysis too extensive, if the help of others is not being offered, then however great may be the person's suffering the law in Britain will force them to live on against their will.

These double standards are the consequence of our politicians' failure to demonstrate the courage of those in Belgium, the Netherlands and Luxembourg. Too many have refused to address the issue or face down the emotive claims and wilful distortions promoted by a minority.

Given that High Court judges in their ruling on the Tony Nicklinson case declared that it was for Parliament not for the courts to decide upon any revision of the law, it is surely ironic that there has been no political challenge to the guidelines published by the Director of Public Prosecutions (DPP).[58] Yet without the specific consent of Parliament this unelected official has, for the best possible reasons, provided an interpretation of the law that has greatly facilitated arrangements for final journeys to be made to Switzerland.

Swiss law is different in principle to that in the Benelux countries, although it pays at least equal respect to the freely expressed wishes of patients. There is no specific law on assisted suicide but a framework is provided by articles within the Swiss Civil Code.

It is forbidden for any doctor to provide 'active' assistance (voluntary euthanasia), but for more than 70 years it has not been illegal to provide someone with 'passive' assistance to die (prescribing the means of death) so long as no selfish motives are involved. The safeguards may be considered less formal than would be required in the UK yet are demonstrably sufficient to command public confidence.

Together with the EXIT organisations that provide a similar service for Swiss citizens of various linguistic backgrounds, Dignitas reports every death immediately to the authorities for investigation by the police and state prosecutors examine every case. The documentation regarding the deceased's medical condition and their clearly expressed wish to die, the fact that they will have travelled to Switzerland specifically for the

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[58] The Queen (on the application of Tony Nicklinson) -v- Ministry of Justice, [2012] EWHC 2381, 16 August 2012.

purpose of doing so, and will have met for two consultations with a Swiss physician independent of Dignitas, usually offers an explanation of the circumstances that is regarded as entirely satisfactory.

Some 1,500 'suicide tourists' from across Europe and indeed the world have now made a final journey to Switzerland. Despite the controversy this has generated in the country, a proposition that it should be made illegal for foreigners to be helped to die on Swiss soil was rejected in a 2011 referendum by 78% of voters of the canton of Zurich. Thanks to them the escape route remains open.

13. The DPP Gives the Green Light

More than 200 British citizens have now travelled to Switzerland to die. Others make the journey every month. Most do so discreetly and without seeking publicity but others have done everything they can to publicise their actions.

Reg Crew, who died in 2003, gave every impression of being outraged that in his own country he would be forced to live on against his will until he experienced a potentially terrible death. He seemed determined to make one last gesture of defiance towards those who refused to respect his wishes.

Daniel James, a promising 23 year old rugby player from Worcester, lost the use of his body from the chest down when a scrum collapsed on top of him during a practice session. After eighteen months of living in constant pain, and several unsuccessful attempts to take his own life, Daniel travelled with his parents to die at the Dignitas organisation in 2008.[59]

The case of Daniel James differed from many in that he was suffering no illness and although paralysed was not terminally ill. His parents assisted him by sending documentation to Dignitas, making payments to Dignitas from their joint bank account, making travel arrangements to take him to

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[59] Crown Prosecution Service, Decision Of Prosecution - The Death By Suicide Of Daniel James, 9 December 2008.

Switzerland, and accompanying him on the flight.

For many years the provisions of the 1961 Suicide Act exposed vulnerable people seeking a release from intolerable circumstances to great stress. It placed at risk of criminal prosecution and imprisonment anyone who assisted a person's suicide. In consequence no doubt some people will have suffered for years rather than let loved ones face this burden. The fact that no action was taken against the parents of Daniel James demonstrated the extreme reluctance of the authorities to apply sanctions in such cases. A prosecution would not have served the public interest.

It was Debbie Purdy's well-publicised battle in the courts to protect her husband from any risk of prosecution that led to formal guidelines being issued on how the law would be interpreted.

In February 2010 the Crown Prosecution Service, having been given the task by the House of Lords, published the 'Policy for Prosecutors in respect of Cases of Encouraging or Assisting Suicide'. This explains the factors that should be taken into consideration, including compassionate motives, the reluctance of the suspect to promote the death of the patient, and the latter's clear and informed wishes.

It also advises prosecutors that the condition of the assisted person - for example whether they are terminally ill or disabled - is not a factor considered relevant to pursuing prosecution. One academic has suggested that "without any restriction based on the victim's condition or experience, the policy is more liberal in this respect than most assisted-dying regimes".[60]

Lord Joffe, the promoter of right-to-die legislation in the House of Lords, has described the guidelines as going beyond the provisions of the bills he has tabled in facilitating the ability of people to secure assistance to die.[61]

Keir Starmer, the DPP, has insisted that the guidelines have neither changed established practice nor have replaced the law, for "that would be for Parliament and Parliament alone".[62]

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[60] P Lewis "Out of Focus", *Solicitors Journal*, 9 March 2010.

[61] Author's interview with Lord Joffe, July 2010.

[62] Starmer, 2011 op. cit.

He says that assisting or encouraging suicide remains a criminal offence, that there must always be a thorough investigation into any suspected cases, and that "any inference that the Crown Prosecution Service has implemented a blanket policy of simply not prosecuting for this offence would be wrong."

It would be very strange if the DPP did not voice such strictures but the fact remains that publication of the guidelines has addressed many of the concerns of those seeking the help of Dignitas. Since they were made available dozens more British citizens have travelled to Switzerland to die and no prosecution for assisting a suicide has been brought. Keir Starmer has described the guidelines as working extremely well. 'They are transparent and consistent, which has helped to build public confidence and to ensure fair treatment for those most affected by the death of someone they love.' In this he is surely right.

But what of those suffering unendurably who want to die at home in their own bed, perhaps with friends and relatives close by? What of those people who cannot afford the cost of a death organised through Dignitas?

For them the law remains as harsh as ever. It may be that prosecutors will no longer pursue cases against those who have assisted a suicide on compassionate grounds but they are adamant that the legal position on 'mercy killing' is unambiguous.

The DPP has said:

> *"If the act that causes a death was performed by anyone other than the person who died, the offence under consideration is likely to be murder or manslaughter. And in such serious cases, it will nearly always be in the public interest to bring criminal proceedings. Any change to this position would be a matter for Parliament."*[63]

A doctor prescribing the means of death to a patient who requested it would certainly face prosecution.

So it's alright to go to Switzerland, but however great the misery do not seek medical help to die in your own bed. Leave your home and your country, or live on here in Britain and suffer.

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[63] *Ibid.*

14. The Opportunity For More Safeguards

While the starting point for framing a UK right-to-die law might be the safeguards used in Benelux legislation this need not be the end. Additional requirements could be introduced to address any concerns that remain. Some of the possibilities have been identified by Professor Raphael Cohen-Almagor of Hull University, whose extensive studies of assisted suicide legislation and practice deserve to be given much greater attention by commentators in the political debate.[64]

It must not be forgotten that most cases of assisted suicide involve people who are already close to death. In a minority of instances, perhaps such as that involving Diane Pretty whose motor-neurone disease ultimately led to her choking to death, it may be possible over several weeks to ensure absolute and formal compliance with all possible requirements, but in many other instances time will be of the essence if the wishes of a patient are to be respected.

There would be no value in Parliament introducing right-to-die legislation that incorporated so many safeguards and requirements that in practice it would be impossible for a patient to have their wishes respected.

With this caveat, amongst the range of additional measures that legislators might include within a right-to-die law are the following:

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[59] Cohen-Almagor, 2009 op. cit.

- A prohibition on voluntary euthanasia: a doctor may prescribe the means by which a lucid individual may terminate their life but even on request may not directly bring about such a death. This is the case in Switzerland and Oregon.
- A requirement that a patient's declaration that they are 'suffering unendurably' be linked to a specific medical condition, and a prohibition that it be solely an expression of being 'tired of life'.
- A requirement that the patient be judged to be terminally ill - although it must be recognised that such a provision could exclude patients who are mentally competent but feel trapped in bodies that do not function.
- Alternatively, a requirement that a third doctor, a specialist, be consulted if the patient's illness is not terminal in order to provide the patient with a full prognosis of their condition.
- A prohibition on a patient judged to be suffering from dementia and no longer competent to reach an end-of-life decision.
- A prohibition on a doctor initiating a discussion about assisted dying options.
- A requirement that patients be advised about palliative care options.
- A requirement to comply with procedures intended to ensure the independence of the second doctor.
- A requirement that a doctor who provides a patient with assistance to die demonstrates to a monitoring body through clear documentation that the patient's wishes were voluntarily expressed, strongly determined, and that there was every opportunity for them to be rescinded. The documentation should include a medical file containing the diagnosis and prognosis of the disease by the attending and the consulting physicians; attempted treatments; the patient's reasons for seeking physician-assisted suicide; the patient's request in writing or documented on a video recording; documentation of conversations with the patient; the physician's offer to the patient to rescind their request; documentation of discussions with the patient's loved ones; a psychological report confirming the patient's condition to verify that the request does not stem from depression; a statement of confirmation from the second doctor to be consulted and evidence that they met the patient concerned.
- A duty placed upon the monitoring body to submit in each case a report on the conclusions of its work to the coroner.

- A requirement that pharmacists report all prescriptions for lethal medication to the monitoring body.
- A duty upon the monitoring body to investigate any suggestions from whistleblowers or others that correct procedures are not being followed, and for it to have the ability to suspend a doctor from practising medicine.

15. The Cruelty Of 'Compassion'

The death of Tony Nicklinson prompted much hand-wringing and many soft words of care and compassion from those who oppose right-to-die legislation. The same was said when Diane Pretty died, as it is every time a public campaigner for reform who has had personal experience of unbearable suffering loses their life.

But soft words serve to disguise the harsh nature of the position being taken.

Tony Nicklinson described his existence as 'a living nightmare.'

> *"Just imagine, if you can, your worst nightmare - then make it worse and you're nowhere near it."*[65]
>
> *"I cannot scratch if I itch, I cannot pick my nose if it is blocked and I can only eat if I am fed like a baby - only I won't grow out of it, unlike the baby.*
>
> *"I have no privacy or dignity left. I am washed, dressed, and put to bed by carers who are, after all, still strangers. You try defecating to order while suspended in a sling over a commode and see how you get on.*

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[65] *The Independent* 23 August 2012 *op. cit.*

> *"I have locked-in syndrome and I can expect no cure or improvement in my condition as my muscles and joints seize up through lack of use.*
>
> *"Indeed, I can expect to dribble my way into old age. If I am lucky I will acquire a life-threatening illness such as cancer so that I can refuse treatment and say no to those who would keep me alive against my will.*
>
> *"By all means protect the vulnerable. By vulnerable I mean those who cannot make decisions for themselves - just don't include me."*[66]

For all their expressions of commiseration, the opponents of law reform would have forced Tony Nicklinson to live on and on. They are convinced that their beliefs should triumph over the wishes of others, however great may be their suffering.

This is not compassion. It is cruelty, and of the highest order.

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[66] Extract from Tony Nicklinson's first statement to the High Court: www.judiciary.gov.uk/Resources/JCO/Documents/Judgments/nicklinson-v-moj.pdf

16. No More Delay - Change The Law

Their pictures were on our TV screens. Their words filled our newspapers. Denied help by their representatives in Parliament, Diane Pretty and Tony Nicklinson went to the courts to try and win the right to be helped to die.

> *"If I am allowed to decide when and how I die, I will feel that I have wrestled some autonomy back and kept hold of my dignity. That is how I want my family to remember me - as someone who respected the law and asked in turn that the law respected my rights."* - Diane Pretty[67]

Both lived to suffer the misery of having their cases rejected.

It is not for the courts to change the law, that is the task for Parliament.

Those who believe that there are no circumstances under which assisted suicide can ever be justified are free to practice what they preach, but they should have no right to impose their personal views on everyone else.

The only justification for MPs not to support right-to-die legislation is to protect the public good. But they should not pretend that there are no safeguards that will do this. The experience of Belgium, the Netherlands and Luxembourg demonstrates that the law can be changed, people

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[67] "Diane Pretty "free at last"", *London Evening Standard*, 13 May 2002.

suffering unendurably can secure help to die, and the vulnerable can be protected.

We can draw on this experience to fashion a law unique to Britain.

The cruelty that poses as compassion must end.

Respect for individual wishes must begin.

> *"I want to have a quick death without suffering, at home, surrounded by my family".* - Diane Pretty[68]

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[68] "Husband's tribute to Diane Pretty", *BBC News online*, 13 May 2002.